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ABSTRACT

This curriculum is intended to provide social service agencies, schools, vocational programs, and other groups concerned with persons having developmental disabilities with guidelines and practical techniques for developing training and support services that encourage choice-making. Emphasis is on allowing people with disabilities to take as much responsibility for their own decision-making as possible, without forcing them into situations where they are unprepared to cope. The first section looks at the agency's role in such areas as staffing patterns, behavior management, and development of a policy on choice-making. A section on beginning to teach choice-making skills considers learned helplessness, a variety of assessment approaches, a case study, and seven sample lesson plans. The following section provides a step-by-step procedure for identifying the individual's communication mode, identifying available options, evaluating options, developing a "plan of action," and evaluating the experience. A choice-making model worksheet is included. Next, ways to implement the curriculum in residential, vocational, and school settings are detailed. The final sections examine choice-making in sexuality and relationships, self-advocacy, and families. Some sections contain references. (DB)

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Teaching Choices

A Curriculum for Persons with Developmental Disabilities

Little Friends Inc.
Naperville, Illinois

November, 1992

This project was funded through a grant from the Illinois Planning Council on Developmental Disabilities.

Preface

In the last few years, the word "choice" has begun to be heard with increasing frequency in discussions of how best to provide services to persons with developmental disabilities. The goal of promoting choice and self-determination is consistent with philosophies such as active treatment, normalization and integration that have been important in shaping practices in this field for years. However, methods for promoting choice-making are in a rudimentary stage of development compared to methods of ensuring active treatment, age-appropriate activities, etc.

This curriculum was developed with the aim of providing social service agencies, schools, vocational programs and other groups concerned with persons with developmental disabilities a starting point for developing training and support services that encourage choice-making. In our agency, Little Friends, Inc. of Naperville, Illinois, the idea of promoting choice is one we have consciously tried to enact in our residential, vocational and school programs for several years now. Along the way, we have found that there are many complex issues involved in teaching choice and in dealing with the ramifications of encouraging choice, and that there are few (if any) written materials available which show how to design training for this specific purpose. Much of what we have learned about teaching choice-making was learned through a process of trial and error; we hope this curriculum will give others a headstart by offering guidelines and practical techniques for teaching individuals how to make informed choices, from the most basic

expression of preferences to the most complex personal decisions.

The mechanics of teaching choice, however, are only part of the issue. Any organization which commits itself to supporting choice-making opportunities and autonomy for individuals with developmental disabilities must realize that this will have its attendant stresses. For one thing, organizational change is never easy. Established attitudes and behaviors die hard, and pronouncements about philosophy don't have much impact unless they are accompanied by a thorough, steady process of examining and changing day-to-day practices and ways of thinking. More importantly, in promoting autonomy for the people we support we must necessarily relinquish some control. This can be threatening to agency staff, parents and teachers who are accustomed to the idea of being responsible for decisions and outcomes regarding the individual. There is a very real basis for the fear that by encouraging individuals to make their own choices, we will lose some of our ability to protect them from the potentially unpleasant or harmful outcomes of these choices.

We hope that this curriculum will help suggest ways to help staff and family be more comfortable with the idea of promoting choice, as well as ways to guide and support individuals in choice-making so that their opportunities for self-determination are maximized while their risks are minimized.

In order to put together a curriculum which addresses as many aspects of choice-making as possible, we sought the help of individuals with expertise in developing progressive and technically sound training and service delivery for persons with developmental disabilities. These

individuals each gave presentations on various topics related to choices, from which we have drawn much of the information conveyed in the following chapters. We have tried, in each chapter of the curriculum, to combine the ideas of the presenters with information from our own experiences supporting choice-making within Little Friends, Inc.

We hope that the product is a guide that is both thought-provoking and practical, and that will encourage people who work with individuals with developmental disabilities to support choice-making through training, policies and everyday interactions.

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Acknowledgements

This curriculum was made possible by a grant from the Illinois Planning Council on Developmental Disabilities. Our thanks is offered to all of the professionals who contributed to the development of this work through their presentations and willingness to share their experiences and expertise in supporting persons with developmental disabilities to make choices in their lives.

The curriculum was developed over a year. The dedicated work of the members of Little Friends, Inc. who served on the Choices Committee made this project a reality.

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Kathleen Carmody	*Director, Choice and Integration Project*
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Introduction

Definitions

CHOICE:

. . . . . *The right, power, or chance to choose*
. . . . . *The act of selecting one option*
. . . . . *A variety from which to choose*
. . . . . *An alternative*

CHOOSE:

. . . . . *To pick out by preference from available objects*

. . . . . *To choose implies the exercise of judgement in settling upon a thing or course from among those offered*

PREFERENCE:

. . . . . *Implies a preconceived partiality for one thing over another*

. . . . . *Does not always connote the actual getting of what one chooses*

. . . . . *Preferences are derived from experiences*

OPTION:

. . . . . *The act of choosing*

. . . . . *The power, right, or liberty of choosing*

. . . . . *An alternative*

Introduction

For most of us, daily life is full of choices. These range from the trivial - "What shall I wear to work?" "What shall I eat for dinner?" - to the profound: "Should I have children?" "What is my religious faith?" Except when our right to choose is threatened, most of us take it largely for granted. Yet people have fought and died for the freedom to make decisions regarding their own lives. Although we may often agonize over the decisions we have to make, few among us would be willing to relinquish our right to make them.

Persons with developmental disabilities, on the other hand, may have a very different experience of choice-making. Although social reform has begun to change some of the restrictive conditions these citizens face, many have been given such a limited range of options that "to choose" may be a verb without much meaning. The number of habilitation training goals that have been written over the years targeting "compliance" gives an indication of the relative value service providers have traditionally placed on self-determination, as opposed to tractability, for people with developmental disabilities.

Although institutional models of service delivery have undoubtedly suppressed choice-making, it is unfair to assume that people working in this field have intentionally and systematically curtailed their clients' rights to self-determination. Part of the problem is that many of the people we work with do not possess the skills they need to identify options and express their choices. When someone is unable to make their preferences known - or is unable to understand

that they have choices at all - it is natural for others to assume the decision-making role for them. It is also unsurprising that family and support people would discount a person's ability to make their own decisions if some of the preferences they have expressed seem childish or irresponsible. So, because of their difficulties in communicating and their lack of information to make responsible choices, people with developmental disabilities may be denied opportunities to choose.

We need to recognize that the lack of opportunity for a person to choose and the belief that they are incapable of making choices are mutually reinforcing. Since many of the people we support have a hard time conceptualizing things they have no direct experience of, it is unlikely that they will express a desire for something if they haven't tried it. Thus, we may be led to believe that they have no preferences, or that they are perfectly happy with the options they have, because they have had no chance to experience other options and thus express no preference for them. This in turn leads us to continue in the assumption that the person has no ability to make choices. For this reason, an essential part of expanding a person's choice-making abilities is expanding their base of experience.

The benefits of teaching individuals to make choices about their lives are numerous. For one thing, the experience of making choices and experiencing their outcomes increases the individual's perceptions of being in control of events that affect him or her. This in turn leads to a greater willingness to experience new things and a better ability to cope with stress. Obviously, the more situations a person is able to experience, the greater the opportunities for success and reinforcement,

the better their chances of attaining new skills and the better their chances of establishing social relationships with others in the community -- all of which are generally considered important goals of habilitation.

In addition, by teaching someone how to express and act on their preferences, we increase the probability that they will have experiences that are reinforcing for them and decrease the probability that they will experience frustration and anger. Similarly, if someone can develop a means of telling us what they like and don't like, it is unnecessary for them to communicate this through behavioral means which may be less acceptable.

Finally, there is the contention that being able to choose for one's self is, in itself, a good thing. Most of us would agree that self-determination is an important factor in quality of life, and that it is worth seeking in and of itself. To this extent, teaching choice-making could be considered worthwhile regardless of whether it has any beneficial effects beyond allowing people to make their own decisions.

Some would say that, after all, if the people we support could make good decisions on their own, why would we be here? From this standpoint, it might seem absurd to teach choice-making, since the reason we are providing support in the first place is because the person cannot function autonomously. We must recognize that making choices is a skill that can be learned, just as other skills that contribute towards independence are learned. Just as we gradually fade our assistance when we teach someone a new skill such as bedmaking, we can

gradually fade our assistance from someone as they learn to make choices.

There is danger in taking an extreme stance on either side of the choice-making issue. While it's unproductive to say that there is no point in providing choices to someone with a developmental disability, it's equally unreasonable to say that someone should be encouraged to make every available choice without guidance, regardless of the ability to comprehend the consequences. If we decide that an individual has an absolute right to make choices regarding his or her own life, and that therefore we will provide the opportunity to do so regardless of how destructive the outcome may be, we are avoiding entirely the issue of competence and our responsibility towards the people we support. As service providers, we need to make sure that "freedom of choice" doesn't become a convenient excuse for abdication of responsibility on our part.

The purpose of this curriculum is to show how support persons and families can give guidance and support to people with disabilities in a manner that allows them to take as much responsibility for their own decision-making as possible, without forcing them into situations where they are unprepared to cope. Through structured training, education and gradual, supported exposure to decision-making situations, persons with developmental disabilities can greatly expand their abilities to become self-determining and responsible citizens, and thus, to live fuller and more satisfying lives.

Chapter 1

The Agency's Role

The Agency's Role [1]

The task of assisting persons with disabilities to make choices that effect their lives requires the commitment of the entire organization. Choice-making cannot occur in isolation and have a meaningful effect on the individual's life. If the administration of the agency does not support the concept of choice, opportunities to make choices will be limited for the individuals served.

The values of the organization will drive the direction of the services provided by that organization. To develop an atmosphere which promotes choice-making and empowerment, the agency must begin by evaluating its mission statement. Does the mission statement support the concepts of choice and empowerment? What are the values of the Administration and the Board of Directors? Do these individuals recognize the importance of choice-making in enhancing the power of the individual?

The values of an organization are transmitted to the staff, parents, and persons served in the agency through the written materials prepared by the organization and through the day-to-day decisions which are made by the agency. Written materials should clearly state the values of the agency and should support the goals of choice and

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[1]Information contained in this chapter is based upon presentations by Barbara Doyle, M.A., Clinical Consultant with the Illinois Department of Mental Health and Developmental Disabilities and a member of Illinois Autism Training Team, and Kathleen Carmody, Director or the Choice and Integration Project, funded by the Illinois Planning Council for Developmental Disabilities.

integration.

Barbara Doyle lists several key questions which should be considered by the agency before a decision is made, to evaluate whether or not the decision will enhance choice-making opportunities or limit them.

Questions for Agency Personnel

- *Is this decision in harmony with the mission of the agency? Does it support the mission statement?*
- *Is this decision in harmony with the values of the agency?*
- *Who will be helped by this decision?*
- *Who will be hurt by this decision?*
- *What will be gained by this decision?*
- *What will be lost by this decision?*
- *How does this decision fit in with your ethics? Does it feel like the right thing to do?*

If the agency personnel review each of these questions before they make a major decision which may affect the lives of the persons served by the organization, then they will be comfortable that the decision made is consistent with the agency's mission statement. If for example, the organization is considering expansion of residential options for persons served, they may need to decide whether to purchase property or rent the property. Would renting property provide greater possible mobility for the resident in the future? Would rental or purchase provide the greatest opportunities for choice for the individuals who are being supported by the agency? Perhaps purchase of property will allow for the agency to offer low income housing options to the individuals who will live there.[2] By evaluating the alternatives using the questions stated above, the organization can thoroughly review the alternatives and the implications of the choices that they will make on the lives of the persons served.

There are many decisions which agency staff must make which can affect the opportunities for choice-making. Deciding which program initiatives available to the organization will affect choices. If an agency pursues the development of large congregate care facilities, choice-making opportunities for the individuals who will reside in the facility will be limited. Supported employment programs offer more

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[2]Example provided by Barbara Doyle, M.A. during her presentation to Little Friends, Inc. on Choices, Downers Grove, IL 1992.

opportunities for choice-making than do traditional sheltered work settings.

Staffing Patterns

Agency decisions regarding staffing patterns and staffing ratios will affect choice-making opportunities. In a residential setting, the decisions regarding employment practices have an enormous effect on the resident care. What hours do the staff work? Is there flexibility in the scheduling of their work hours which affords the residents the opportunity to participate in activities and events throughout the day? The staffing ratio will affect choice-making opportunities because a staff member will not be able to support one individual's choice as easily when he has the responsibility for eight others at the same time.

The values and attitudes which are held by the agency will have the greatest affect on the direction and scope of services which are provided. An agency which values choice and integration will move away from service models which limit personal involvement and choice-making opportunities for persons served. New initiatives will be directed toward smaller placements, both residentially and vocationally.

Independence vs Interdependence

The attitudes of the staff will be apparent when you consider the question "Whose program is this?" Who in fact owns the program? What are the desired outcomes of the program? What is the goal? Is

the goal total independence or interdependence? A goal of independence may be unattainable for many individuals in a given sphere of training. No one is independent in all areas of his life. One person can make simple plumbing repairs around their home while another person calls a professional plumber to provide help and assistance to properly maintain their pipes and water services. That individual is dependent upon the plumber. Many persons regularly use the services of caterers, housekeepers, financial planners, lawn services, gardeners, carpenters, electricians, etc. We are dependent upon these professional to assist us in our daily lives to fulfill those functions which we have neither the time nor the talent to complete independently. We are not totally independent. There is no reason that persons with disabilities need to be totally independent either. It is perfectly acceptable to receive support services in some areas and be independent in others.

Once an agency has adopted the values of choice and integration, the task becomes operationalizing these values. Without a plan to insure that the agency values will be upheld, maximum opportunities for choice may not occur as frequently as desired. The plan will include several elements including personnel recruitment, staff training, case management responsibilities, behavior management policies, human rights policies, and quality assurance measures.

Personnel Recruitment

The first key element to this plan involves personnel recruitment. Personnel must be recruited who have similar values to that of the

agency. If persons are hired who value control of situations, who are overly authoritarian or parental in their interactions with others, or who avoid all risks in life, then it may be very difficult for them to be open enough in their interactions to allow the persons they support to have choices in their daily routine. Persons should be hired who have attitudes and personal philosophies which are compatible to those of the agency. Once hired, staff training is very important to insure that all staff are informed of the agency's mission statement, values and attitudes regarding resident services. These values must be clearly communicated to all levels of staff as soon as possible after hiring so that from the very first day on the job the staff are trained to treat the individuals they support with respect and dignity.

Futures Planning

Beyond defining the role of a support staff member, the agency should have policies and procedures in place which govern the day-to-day activities in a given program and insure that the values of choice and integration are offered to the persons served. Such practices as futures planning will help to insure that the resident's program plan is individual and geared to meet his or her desires for the future. Where do they want to live? Where do they want to work? How can the agency staff support the individual to achieve his goals? What services are needed? What skill development must occur? What additional advocacy must occur on behalf of the individual for the goal to be accomplished? (Examples of futures planning forms used by Little

Friends, Inc. are included at the end of this chapter.)

To assist the individual with the futures planning process a client advocate should be obtained. The role of the advocate is to insure that the individual has the opportunity to state his goals at the staffing; to insure that he is heard. The advocate, if they are a strong advocate, can insure that when a conflict occurs between the needs of the organization and the wishes or needs of the persons served that the issue gets a full review. The advocate may assist the individual in asking for a review of a decision which the person served views as unfavorable.

To allow for a review of decisions made which affect the lives of the persons served at least two mechanisms need to be in place: the Behavior Management Committee and the Human Rights Committee. Each plays a separate and distinct part in insuring that the persons served receive the maximum opportunities for choice and integration. These committees, if they are functioning well, insure that the values that the agency aspires to are in fact, and in practice, carried out by the staff.

Behavior Management

The Behavior Management Committee provides technical review of behavior modification programs which use restrictive procedures. Generally each agency defines the procedures which require review. Best practices would mandate that the agency review all procedures which use aversive techniques and which limit the individual's choices. For example, behavior programs which target behaviors such as "non-

compliance with staff directives" would require review to insure that the behavior being modified does not inhibit the individual's right to refuse an activity or to communicate in a non-verbal manner his dissatisfaction with a current event. The behavior management policies of the agency should include a requirement that a functional analysis of the targeted behavior has been completed which takes into account the communicative intent of the action.

Human Rights Committee

The agency's Human Rights Committee provides a valuable tool in the overall quality assurance plan. The fundamental role of the Human Rights Committee is to insure that the agency policies and practices do not infringe upon the rights and freedoms of the service recipients. In addition to this role, the agency's human rights policy can be written to insure that individual service recipients who have not been able to settle disagreements on the content of their service plan are able to have their grievance heard by the Human Rights Committee. The individual's advocate will assist him to present his position clearly to the committee members. The advocate supports the individual throughout the meeting to insure that the individual understands the information presented at the meeting.

Choices Policy

An agency can take additional steps to insure that the values and attitudes conveyed in the mission statement are upheld by all staff through the development of a policy governing choice-making for the persons served. Kathleen Carmody, Director of the Choice and Integration Project stresses that in developing a policy on choice-making the agency may wish to seek the input of a broad cross section of persons who will be affected by the policy: parents, consumers, consumer advocates, direct care staff, and members of the general community. To develop a policy on choice will require that the agency think through the practical implications of choice on the lives of the persons served. How will the agency determine who is capable of making "informed" choices? Is there an operational definition? What will be the administrative response when the individual makes choices which could bring him or her harm? What will happen when the individual's values are in conflict with the staff's values? What will occur when the staff's values are in conflict with the agency's? How far will the agency go in supporting choices which involve risks to the individual?

Kathleen Carmody, Director of the Choice and Integration Project which was funded by the Illinois Planning Council on Developmental Disabilities presented a sample Choice Policy. This policy would need to be adapted to the unique characteristics of any given agency.

CHOICE POLICY[3]

(Agency) is committed to soliciting and respecting the choices of persons served. Persons will contribute in designing their own service package. This includes participating in the selection of their home, house mates, furnishings, staff, day time activities and goals/objectives. No person will move into a home which they have not yet visited and approved, nor will they live with someone whom they have not met.

Recognizing that many persons with disabilities have had limited opportunities to make choices in the past, an important function of (Agency's) services is to create opportunities for people to develop skill in this area. This includes exposing people to the different options available to them in the community (e.g. jobs, recreation, education, etc.), as well as using every day situations to teach decision-making skills.

Staff will assist people in carrying out their choices by analyzing the consequences of actions, assisting people in attaining skills necessary to implement choices, and discussing other possible options available to the person. The distinction between "risk" and harm" will be discussed with each participant. (Agency) will not support people in carrying out choices which are considered likely to bring harm to the person or others.

When it is necessary for staff to make choices on behalf of participants, they will do so in the best interest of the person. This means they will respond to situations and opportunities in the manner which they think the participant would want. Choices made in the best interest of a participant will be based upon staff's knowledge of and experience with the person. These choices shall be consistent with the goal of assisting and supporting people to become as capable as possible.

---

[3]Created by Kathleen Carmody, Director, Choice and Integration Project, funded by the Illinois Planning Council for Developmental Disabilities.

LITTLE FRIENDS, INC.
Futures Plan Goals

Name: _____ Date: _____

The following goals are ones that should direct service provision efforts over approximately the next five years in order to achieve the individual's expressed lifestyle goals.

Expressed Future Goals:

Day activity goal:_____

Key elements of the goal which make it important for the person:

Summary of team's discussion regarding the expressed goal:

Residential goal: _____

Key elements of the goal which make it important for the person:

Summary of team's discussion regarding the expressed goal:

General Action Plan

In this area, provide a general description of some of the potential actions that could be taken to assist the person in working towards these futures goals. Possibilities include: assisting the person to apply for residential or vocational programs, helping them to secure financial assistance, training areas to be addressed, etc.

Action:

Responsible program(s):

Annual Updates:

Action:

Responsible program(s):

Annual Updates:

Action:

Responsible program(s):

Annual Updates:

Action:

Responsible program(s):

Annual Updates:

Action:

Responsible program(s):

Annual Updates:

Signatures/Titles of Team Members in Attendance:

Name	Title
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Revised 9/92.

LITTLE FRIENDS, INC.
Characteristics Of Ideal Lifestyle

NAME:_____ **DATE:**_____

This form is reviewed with the person by the advocate in advance of a staffing. The chairperson should indicate on each question staff and family comments if the person has not been complete in their answers or if the staff or family differ in their opinions of what is best or needed for the individual.

1. Please describe the town in which you prefer to live. Consider things like how close it is to your family, what services you desire being near, cultural and recreational events you would care to be near.

_____
_____
_____
_____
_____

2. How many roommates would be best for you? Consider things like how many you need to share expenses and work in the home and how many you desire for companionship.

_____
_____
_____

3. If you feel you need staff support to maintain your lifestyle, how many hours per day or week do you desire?

_____
_____

4. What type of training do you feel that you need to achieve and maintain the lifestyle you are attempting to attain?

_____
_____
_____

5. Is a barrier free residence required?

_____
_____

6. What are your needs for transportation?

_____

Characteristics Of Ideal Lifestyle
PAGE TWO

7. Do you have a roommate preference?

_____

_____

8. Please describe support services needed. These can include medical support, psychological services, behavior management, psychiatric services, occupational therapy, physical therapy and so on.

_____

_____

_____

9. Please list other needs and preferences in terms of living arrangement that have not yet been identified:

_____

_____

_____

10. Can any residential setting which is currently in operation and which meets all of your needs be identified? If so what:

_____

_____

11. If not, what is the program operating that is closest to your preference?

_____

_____

12. Please describe area in which you prefer to work or have day activity? Consider things like how close it is to where you live or want to live, and how available transportation is.

_____

_____

_____

_____

13. Describe the size of the workplace or day activity you desire. Consider things like how many persons you work best near.

_____

_____

Characteristics Of Ideal Lifestyle
PAGE THREE

14. If you feel you need staff support to teach you the job and maintain you on the job, please tell us how many hours per week of staff time do you need?

15. Describe the job or day activity you want. What type of work do you want to do? What is your vocational goal? Do you prefer working with people or things? Do you need to have a sit down job or one in which you move around a great deal? Can you work full or part time? Do ycu need a barrier-free workplace?

16. What are your transportation needs?

17. What other needs and preferences do you have for work or day activity?

18. Is there any day program or setting that currently exists that can meet your needs? Is so, what is it?

19. If not, which is the closest to meeting your needs?

Chapter 2

Choice-Making: Where to Begin

Choice-Making - Where To Begin![4]

It is well recognized in the area of developmental disabilities that all individuals must be given maximum control over their daily lives. It is only through gaining this control that an individual can truly understand that he can impact on others in his environment. This knowledge of the ability to impact on another's behavior is what communication is all about. One way to let an individual understand the power of communication is through providing ample opportunities for choice-making throughout an individual's day and allowing him to experience the natural consequences of his choice. A study was done in 1987 (published in JASH) which looked at how often children in a pre-school setting indicated a choice or preference, and how often the staff acknowledged and responded to these initiations. In general, the study found that in structured situations, staff responded only approximately 15% of the time and in unstructured situations approximately 7% of the time. Some reasons for why staff responded so infrequently include:

A. The children's means of indicating preference (e.g., how they demonstrated their choices) were subtle or unconventional and thus not interpreted as an initiation of choice. For example, a child may just go and stand by the

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[4]This chapter written by Jenny Potanos, M.A., Director of Communication for the Children's Services Division of Little Friends, Inc. Mrs. Potanos is a member of the Illinois State Training Team for Autism and credits the Autism Training materials as the inspiration for much of this text.

snack cabinet to indicate he'd like to have a snack; or he may bite his peer to communicate his preference to not have that peer in his proximity.

B. The staff may be so set in following their agenda that they may be unwilling to acknowledge a child's initiation of choice. For example, if a child comes into a classroom at 9:00 and goes and gets his placemat to indicate his preference for a snack, his teacher might be unwilling to postpone the scheduled 9:00 activity, "circle time," to allow him the natural consequence for his indication of choice.

C. Often staff in a human services field view themselves as "caretakers" and may be unwilling to allow an individual to experience what they may perceive as a "wrong choice." For example, if at dinner, an adult in a group home touches his line drawing of milk, but the staff person "knows" that he dislikes milk, they may give him juice instead to "be sure that he is taken care of."

Learned Helplessness

Although often unintentional, this inability by support staff to respond to and acknowledge choice can create a condition known as "learned helplessness" (Seligman, 1975).

Basically, learned helplessness results from a belief that nothing one does makes a difference, and the overall attitude may be one of "no

one understands me;" "in the end, someone else will be responsible for taking care of me and getting me what I need," etc.

Obviously, it is easier to acknowledge and respond to individuals' indication of choices when they are exhibited in more conventional communicative forms (e.g., verbal, written). It becomes more difficult to acknowledge choices for individuals who use less conventional means of communication or are cognitively and motorically challenged. Therefore, the first step in setting up choice-making situations involves assessment.

Assessment of Communication Skills

A variety of communicative, cognitive and motoric areas should be assessed prior to initiating formal choice-making programs. Attached is a format which delineates specific questions to ask of those involved in supporting an individual. If possible, these questions should be asked of as many support persons as possible, as an individual may demonstrate different strengths and weaknesses with different people.

It is essential to determine an individual's level of symbolic representation. In other words, at which level does he understand that a symbol represents a person, action, idea. For example, the verbal label "ball" symbolizes to most people a small round object that can be thrown. Additionally, if shown a picture of a ball, that would also represent that same object. For some individuals with challenges, the verbal label "ball" may not reference them to that object, yet a picture of the object may. Therefore, offering a person a choice between playing

"ball" or watching "T.V." through the verbal channel may be very difficult for him. However, if offered that same choice through pictorial means (e.g., showing him a picture of ball and T.V.) indicating preference may be much simpler. Because it is essential that choices be presented in a way that the person understands, assessment of level of symbolic representation should be done.

Schuler-Borman Cognitive/Conceptual Matching Probe

It is recommended that a format such as the Schuler-Borman Cognitive/Conceptual Matching Probe[5] be used to determine if an individual understands the following symbols (e.g., For Ball):

- Concrete Verbal Labels ("ball")
- Abstract Verbal Labels ("round, can throw it")
- Exact Match Pictures (picture which looks exactly like the object)
- Non-identical Picture (blue ball for red ball)
- 35 mm photo of object
- Polaroid photo of object
- Black and White Line Drawing of Object
- Concrete Written Label (the written word "ball")

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[5] Based upon the work of Schuler, A., 1979 and Borman and Schuler, The interrelating between cognitive and communication development - some implications from the study of a mute autistic adolescent., 1983, an unpublished manuscript from the University of California at Santa Barbara.

- Abstract Written Label (written "It's round and children throw it)

Using the format mentioned above, the individual is asked to non-verbally match actual objects and the symbols. Because this assessment is not language-based, allows the individual to use actual objects, and focuses on the visual modality (which is often the strongest modality for many individuals with cognitive and communication challenges), often learners are easily able to "show what they know."

However, if a formal assessment is not successful, individuals can be assessed informally in highly motivating situations. For example, an individual can be presented with photographs of his favorite foods. Does he quickly learn to touch the photo to gain the item? If yes, then that level of symbolic representation is probably one that he understands, at least in that particular context.

Communicative Functions of Behavior

Another important area to assess is the means an individual uses to communicate. In other words, how does he communicate? Many of our learners use less conventional appropriate and inappropriate behaviors to communicate a variety of different functions (the person's reason for communicating). It is important to look at the communicative functions of an individual's behaviors in order to then shape those less appropriate behaviors into more conventional means to indicate choice.

For example, if it is determined that an individual throws his materials off his work table to choose a "break" time, it may be decided

to implement a "bell program" where he is systematically taught to ring a bell to gain a break. On the other hand, if he throws his materials to request attention, a different program would need to be implemented. Attached is a Functions of Behavior Graph[6] which can be helpful in assessing the functions of an individual's behavior. Again, if possible, this graph should be completed by all those involved in supporting an individual as a behavior may serve varying functions for an individual in varying environments.

Assessment of Motoric Functioning

An individual's motoric abilities should be assessed in order to provide choices in a manner conducive for response. Can the person use a pointing response, or does he need to actively manipulate the symbol to make a choice? (If he cannot point, a laminated choice board which requires an accurate pointing response would be ineffective.) Is he able to scan horizontally and vertically? (Usually, individuals are offered choices using a horizontal scanning pattern, when in fact, the person may only scan vertically.) How many symbols can a person scan at a time? Oftentimes, an individual is unable to make a choice because the choice field contains too many items for him to scan at once. Do his choice-making abilities improve if the items are held closer together or farther apart? Can he make a choice given some facilitation? (Physical support and resistance while accessing an augmentative communication

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[6]Created by Anne Donnellan, Pat Marenda, et. al, University of Wisconsin at Madison, 1987.

device.) Does a person have sufficient strength to turn the pages of a choicebook? And does he have object permanence to know that the symbols continue to exist when the book is closed? These are some initial areas at which to look. Often an occupational therapist can provide insight into how an individual can scan, as well as the best response mode to expect from an individual.

When to Offer Choices

Once an initial assessment has been done, it is important to offer choices across an individual's day in a similar method in each environment. It is important to realize that initially an individual may not be consciously indicating a choice, but may just be expressing a preference for an object or person, etc. (Developmentally, it is not until a person is at Piaget's Sensori-Motor Stage IV that he consciously begins to indicate choice.) That does not mean that he should not be provided with preference indicating situations across his day. Initially it is critical that an individual's expression of preference or choice be responded to consistently and that the natural consequence be given in order to help the individual understand that he can express choice in a positive manner.

For example, if an individual taps at the door to indicate his choice to go out to the playground, INITIALLY, this behavior should consistently bring about the desired trip to the playground. This requires that support personnel be flexible in their agendas to allow the person to experience the natural consequence of his choice. Eventually,

when the individual clearly understands that the behavior gets the action, he can be told or visually shown that he has to wait. If, however, that subtle behavior of tapping the door to go outside is not responded to, the person may use less appropriate means to indicate his choice, such as running outdoors, throwing a tantrum, etc.

It is important that support personnel are not so rigid in their agendas that they do not allow for these natural teaching situations to occur.

Additionally, it is important to intentionally program for teaching choice-making. One way to do this is to schedule choice-making periods into a person's day. Often, it is recommended that a person's daily schedule reflect built-in choice-making periods. For example, a schedule may look like this: Breakfast: Make Bed: CHOOSE Clothing: Groom: CHOOSE free time activity: CHOOSE Chore: Go to Grocery Store: CHOOSE Lunch items, etc.

Often "Activity Choice Books" which contain a variety of choice activity pictures are used to regularly give individuals control over their day. This is not to imply that a person's day should be totally unstructured and at his control to choose, but rather, structured choice should be built into his day. (For example, staff can allow a person to choose what he wants for lunch, but they can determine what the choice field of lunch items contains.)

Concepts to Teach

It is important to teach all individuals who are communicatively, cognitively, or motorically challenged a way to communicate when they choose to end a task. Some successful strategies include having an individual place items in a "finished basket" when they want to be done with a task, or teaching them to touch a STOP sign, or place the picture of the task in a "STOP envelope" when they want to indicate desire for termination.

It is also important to teach concepts such as "more," "I don't want to," "I like," etc. Even individuals who appear to have good verbal communication skills are often unable to verbally state their like or dislike of activity, object, or person. Often these individuals may verbally indicate that they want an item or activity, but when presented with that choice, will use other behavioral means to demonstrate their displeasure. In these instances, it is often preferable to give the individual other means to make a choice (e.g., through pictures or written words) and to actively teach them to verbally state dislike. For example, if a highly verbal individual is presented with picture choices of Coke, which he likes, and Sprite, which he dislikes, allow him to non-verbally indicate his choice, but then model verbally, "I like Coke," "I don't like Sprite."

There are many naturally occurring instances in a day where a person can be given opportunity for choice. He can choose food and drink items. He can indicate what he wants to wear. (To avoid situations where a person may choose mismatched clothing, try to

arrange clothing in a way that all pants are neutral solids, and all shirts are coordinated patterns; or, color code clothing so that any shirt with an orange label matches any orange labeled pants.)

Give the individual choice in his free-time activities. Allow him to choose partners for an activity or outing. Often it is recommended that an individual's daily schedule have names or pictures of staff and peers that can be chosen to participate in a particular activity. Build choice-making into his schedule in order to allow him to choose the next activity, or to choose the sequence of steps in an activity. Often support personnel get so "caught up in" task analysis, that it is forgotten that there is more than one "right way" to complete a task. For example, it does not matter when doing laundry if the soap or the clothes go in first; yet, often staff exert control over individuals with challenges by dictating this order for them.

In teaching choice-making, a simple initial mode of providing choice is to offer two actual objects to the individual and ask, "What do you want?" This method does not require the person to understand any object labels, it does not require a knowledge of level of symbolic representation, but rather only requires him to use a very basic response, such as an eye gas, a reach towards the desired object, etc.

Obviously, one difficulty with offering choice-making opportunities to individuals at this level is the problems that arise in trying to represent all activities through actual objects. One way to alleviate this problem is to begin to associate specific objects with particular activities. For example, if every time a person has snack, he uses a yellow cup, then that cup could be used to represent snack in a choice-making

situation. Or, if an adult always wore a certain shirt when he went bowling and his swim trunks for swimming, then those clothing items could be used to give him a choice of which rec/leisure activity he prefers. With individuals at the object level for choice-making, it is important to offer the choice immediately before the activity is to occur and to then use that object in the activity.

Yes and No Questions

Oftentimes, choices are presented to individuals in such a manner as to require understanding of question formation and the ability to answer yes or no. For example, a person may be told, "We have chips or popcorn. Do you want chips?" Although this is a perfectly acceptable way to offer a choice, it is important to realize the advanced language skills which are embedded in this format. Often individuals who are echolalic, will repeat the last choice offered, (e.g., will say "NO" because question was phrased as "Yes or No?") or will repeat the entire "yes or no" question. In these instances, it may be better to back up and offer choice non-verbally by presenting actual objects or levels of symbolic representation that the person understands and allow him to make his choice non-verbally.

It is critical to provide logical, natural consequences when a person indicates a choice. Every choice-making situation should have a natural consequence. It is imperative to not "second guess" the learner. For example, if a staff person knows that a child hates hamburgers, and yet, he selects that as his restaurant meal choice, staff

should not decide that in reality the child does not want hamburgers. Rather, the child should be given the natural consequence of his choice in order to help him learn that his action is meaningful. If in fact, the staff decided to not get the child the hamburger and provided him with a preferred item, staff would be teaching that child that "It doesn't matter what you choose, in the end I will be responsible for seeing that you get what you want." If the child becomes upset with his choice, then, if at all possible, staff should present the choice situation again and assist the child in making the desired choice.

There is no such thing as a "wrong choice." Often support persons feel that they are giving individuals a choice, when in reality, there is a right answer to the proposed "choices." For example, if a person is tantrumming and staff say, "You have a choice. You can either calm down and go to gym or you can go to time-out" obviously, the correct answer is calm down and go to gym. Time-out is not the person's choice, but rather the staff selected "punishment." A better way to view that situation might be to analyze what about the gym is possibly causing the tantrum. Perhaps the space is too overwhelming for the person. Then, a true choice might be to offer the person the opportunity to have physical education in the gym, a small weight room, or outdoors. (This could be done using photos of the three locations, or physically taking the child to each location and "reading and interpreting" by his behavior which he prefers.

Functional Analysis Of Communication Skills

The functional analysis of communication skills refers to the methods of determining how individuals process information both receptively and expressively. This analysis helps staff assist individuals in indicating preferences and choices in their personal lives.[7]

I. Assess the ability to follow verbal directives and information.

A. What is the ability to follow concrete directions?

1. Can the individual follow a one-step direction? Ex.: "Please pick up the ball?"
2. Can the individual follow a two step direction? Ex.: "Can you go to the gym and get the ball?"

B. What is the individual's ability to follow abstract directions?

1. The use of longer directives, and/or idioms. Having the ability to determine the meaning of an accepted phrase, or expression contrary to the usual patterns of the language or having a meaning different from the literal. (Ex.: "It's raining cats and dogs")
2. Abstract concepts dealing with time: Ex.: "What did you have for lunch yesterday?"
3. Understanding the use of slang in every day language.

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[7]Created by Jenny Potanos, M.A., and Kristina Lind, M.S.W., Little Friends, Inc., 1992

C. Quantitative concepts: The numerical concepts dealing with abstract to concrete perceptions:

1. Abstract numerical concepts: Ex.: "Give me a few cups, please." "Who has the most cards?"
2. Concrete numerical concepts: Ex.: "Can you set the table for 5 people?"

D. Qualitative concepts: the use of color, size and/or shape. Ex.: "Take the biggest bowl out of the cabinet."

E. Temporal concepts: Prepositional concepts dealing with time. Using words such as before after during, or until. Ex.: "Please put the egg in the batter before the sugar."

F. Spatial concepts: The use of prepositional concepts dealing with spatial perceptions such as in, on, above, etc. Ex.: "Put the sugar in the bowl."

II. Assess where the verbal direction is breaking down.

A. Does it help if individual is provided with a visual or gestural cue? Ex.: A gesture to the area or someone else modeling the directive.

B. Does adaptation facilitate task completion? If so provide a visual cue. Ex.: A picture book of the steps involved in the task or using color cues for sorting laundry.

III. Assess the level of symbolic representation: Does the individual understand that the symbols represent an object or activity?

A. The following are possible activities that may help the individual interpret the situation. These activities are ranked from the simplest to the more complex:

1. Cut out pictures of the object or activity.
2. Photograph of the object or activity.
3. Line drawing.
4. Single written word.
5. Written sentence.

B. If the individual would be more independent as a result of the visual cues, the staff can reduce direct instruction and verbal prompting.

C. The hierarchy of symbolic representation is useful for many but not all disorders. Individuals with autism, for example, do not necessarily follow the "simplest to the more complex hierarchy."

D. An individual's symbolic representation may vary across environments and activities; e.g., an individual may verbalize a preference about dinner items or who to sit near, but may need visual cues when discussing community outings or preferences about work. The appropriate type of cuing to be used should be dependent upon the individual's level of understanding of concrete and/or abstract ideas.

IV. Assess problem solving ability:

A. Can the individual formulate a solution to the problem?

B. Can the individual verbalize the solution or does the individual solve the problem by manipulating the solution?

C. Would cue cards help when the individual cannot access the words? e.g. If the individual cannot verbalize, "I need

help;" when a problem occurs at a job site using an "I need help:" cue card may be helpful to cue him to verbalize that need.

V. Assess visual processing: Some individuals require that visual cues be further apart, larger, smaller, closer together, etc.

VI. Assess response mode...observe how preferences are indicated.
   A. Eye gaze
   B. Handing something over
   C. Slapping
   D. Verbalization
   E. Posturing

VII. Assess environmental condition: Does the environment influence the way an individual processes a situation.
   A. Can an individual transfer a task across environments?
   B. Is the individual influenced by a change of staff?

VIII. Assess processing time:
   A. How long does it take to make a choice?
   B. Always allow a minimum of 3 minutes before prompting or assisting in the choice-making process.

COMMENTS: _____

_____

_____

Functional Analysis Of Communication Skills Checklist

Name: _____

Recorder's Name:_____

Date: _____

1. What is the individual's understanding of abstract concepts?

   _____

2. What is the individual's understanding of quantitative concepts?

   _____

3. What is the individual's understanding of qualitative concepts?

   _____

4. What is the individual's understanding of temporal concepts?

   _____

5. What is the individual's understanding of spatial concepts?

   _____

6. Do visual cues help?

   _____

7. Which level of symbolic representation is most helpful to the individual?

   _____

8. How are responses indicated by the individual?

   _____

9. What environment is most conducive for the individual to understanding the directive/request?

_____

10. How long does it usually take the individual to make a simple choice?

_____

11. How does the individual ask for help or state he does not understand?

_____

12. How does the individual ask to stop an activity?

_____

13. How does the individual indicate he needs more information?

_____

14. How does the individual protest a situation?

_____

15. Are there specific behaviors that consistently serve as a form of communication? Describe below.

_____

_____

COMMENTS: _____

_____

Assessment Of Communication Skills
Goals

1. Assess receptive language.
   How well does the client understand verbal language or visual communication?

2. Assess expressive language.
   How does a client ask for help?
   How does he protest?
   How does he ask to stop an activity?
   How does he ask for more information?

   REMINDER: The individual may communicate verbally, non-verbally, or through his/her behaviors. (See Item #15 on worksheet for additional explanation.)

NOTE: Even verbal, high functioning individuals do not always use conventional methods for expressing their needs, feelings, or requests. We can help these individuals develop conventional methods of communication that would be both beneficial to them and more readily accepted by the community.

FUNCTIONS	BEHAVIORS: Aggression	Bizarre verbalizations	Inapp. oral/anal behavior	Perseverative rituals	Self-injurious behavior	Self-stimulation	Tantrum	Facial expression	Gaze aversion	Glazing/staring	Gesturing/pointing	Hugging/kissing	Masturbation	Object manipulation	Proximity positioning	Pushing/pulling	Reaching/grabbing	Running	Touching	Delayed echolalia	Immediate echolalia	Laughing/giggling	Scream/yell	Swearing	Verbal/physical threats	Whining/crying	Complex sign/approximation	One word sign/approximation	One word speech/approx.	Picture/written word
1. INTERACTIVE																													
A. Requests for																													
Attention																													
Social interaction																													
Play Interactions																													
Affection																													
Permission to Engage in an Activity																													
Action by Receiver																													
Assistance																													
Information/Clarification																													
Objects																													
Food																													
B. Negations																													
Protest																													
Refusal																													
Cessation																													
C. Declarations/Comments																													
About Events/Actions																													
About Objects/Persons																													
About Errors/Mistakes																													
Affirmation																													
Greeting																													
Humor																													
D. Declarations																													
About Feelings																													
Anticipation																													
Boredom																													
Confusion																													
Fear																													
Frustration																													
Hurt Feelings																													
Pain																													
Pleasure																													
II. NON-INTERACTIVE																													
A. Self-Regulation																													
B. Rehearsal																													
C. Habitual																													
D. Relaxation/ Tension Release																													

Student _____ Date _____ Time _____

Activity _____

Case Study

Francine is a young woman with a diagnosis of mental retardation at the severe level who lives in a group home. Although Francine has some expressive speech (mostly single-word utterances), she largely communicates non-verbally. Staff at the group home are concerned because Francine is displaying an increasing amount of aggressive behavior towards them when they try to work with her. For instance, when they try to teach Francine to make her bed, she will cooperate for a short period of time then try to scratch or hit. This is problematic not only because of the danger of injuries to staff, but also because of the difficulty in providing Francine with any training.

In analyzing reports of Francine's behavioral incidents, it becomes clear that aggression occurs almost exclusively in the context of training programs, such as bedmaking, self-medication and cooking. It also is evident that the typical response to Francine's aggression is for staff to first try to continue engaging her in the activity, but ultimately to end the training session when it appears that Francine's behavior is becoming too extreme. The behavioral consultant points out that this pattern of response provides negative reinforcement of Francine's aggression: assuming that Francine doesn't enjoy the activity, termination of the activity contingent upon her aggression reinforces the aggressive behavior. One possibility would be to avoid doing any training with Francine, but this is not in keeping with the group home's licensure standards, nor is it in Francine's best interests.

Since Francine's behavior seems to have the communicative function of letting staff know that she wants to end an activity, the decision is to try teaching her a more acceptable way of communicating this. The staff make up a small "stop" sign for Francine that can be kept at hand whenever they do training with her. Initially, the sign is made available throughout the training session. As soon as Francine begins to show any sign of resisting the activity or becoming aggressive, staff prompt her to touch the stop sign and say, "That's all." They then cease the training session and remove the materials or their own presence. In order to avoid further negative reinforcement of the aggressive behavior, if Francine actually scratches or hits, the staff tell her "no" in a firm but neutral manner and remove the stop sign for a few seconds. Then Francine is prompted to return to the task, the sign is again made available and staff prompt her to touch it, thereby ending the activity.

Once Francine learns to use the stop sign to communicate her desire to end an activity, staff gradually lengthen the amount of time they work with Francine before they make the stop sign available. In this way, they are able to slowly build the amount of time Francine tolerates training.

Sample Lesson Plans

Lesson Plan #1

Objective: To begin to introduce pictures with a student to improve the student's concept of a picture representing an activity.

Materials: Pictures of wagon, swing, slide, bubbles.

Procedure: The following pictures will initially be used with the student to represent free time activities: wagon, swing, slide, bubbles. During free time, the student will be shown 2 pictures of free time activities. Staff will prompt the student with "What do?" If the student does not make a choice, staff should guide the student's hand to a picture and say, "Look, bubbles." Then the activity should be performed with the student in a playful manner; the activity should not be continued to a point where the student is not somewhat enjoying the activity.

Whenever staff wants to participate in one of the pictured free time activities with the student, the pictures should be used with her to consistently orient her to picture representation.

Lesson Plan #2

Objective: Given line drawing representations of available choices, student will choose which activity or snack item he would like. Student will spontaneously verbalize his choice given line drawings as a visual cue.

Materials: Notebook

Procedure: Student's "choice-notebook" will be located in the kitchen area. At designated times during the day, the student will be given this notebook and allowed to make choices in his daily schedule. Initially this choice notebook will be used with the student during:

A. Snack time

B. Scheduled "activity-choice" periods which will be indicated by his "activity-choice" pictures on his daily schedule.

Before each of the above mentioned times, staff should make sure appropriate and available choices are placed in the student's notebook. Staff should present the notebook to the student and tell him, "Your time to choose. What do you want to (do; eat; etc...?") If student indicates a choice by pointing or verbalizing, staff should immediately praise the student for making a choice and get him that activity/item. While getting the item, staff should attempt to get the student to verbalize his choice (if he has pointed) in a casual manner, but should NOT pressure the student to give a verbal response spontaneously or

following a model as the student has already indicated his choice non-verbally.

If the student does not point to or verbalize a choice, staff should wait a few seconds and then give the student the same natural verbal cue as above while physically assisting him in pointing to a picture.

Lesson Plan #3

Objective: Recently, the student has begun to communicate a desire to use the toilet by pulling her pants down or leading staff by pulling her pants down. Although this is very encouraging, it is also necessary to begin to pair these behaviors with a more appropriate means of communicating this need.

Materials: None

Procedure: Immediately after the student has pulled her pants down, either spontaneously or when staff takes her to the toilet, the student should be shown the toilet picture which will be placed in the bathroom. Staff should verbalize "Toilet, (student's name) has to go toilet." While touching the picture, attempt to have the student model the action of touching the picture. If she does not model, guide her hand to the picture and repeat, "Toilet, go toilet." The have the student use the toilet.

Lesson Plan #4

Objective: To increase the student's ability to use pictures to get needs/wants met.

Materials: None

Procedure: Periodically, throughout the day, the student can be offered a choice of a particular food item or a drink. This should be done informally, and the student should not be "forced" to choose one or be restricted to the table.

Get two pictures and show them to the student. Place the pictures of the free-time choice on the board if they have velcro, or else on the floor or a table. (1 food item and a drink). Ask the student, "What want?" If the student does not choose a picture after several minutes, remove the pictures and say, "(Student's name) does not want snack." If it is apparent by the student's action (e.g., head banging, leading you to drink) that she really does want a snack, present the pictures to her again. If again, after several minutes, the student does not choose a picture, guide her to a picture and then give her that food/drink item. (If it is evident that she does want a snack).

Lesson Plan #5

Objective: In order to begin to introduce the student to a picture system, as well as to increase the student's ability to indicate choices for activities in a more conventional manner, an activity choice book will be used with the student throughout the day.

Materials: Picture system

Procedure: Initially, the student will choose from a picture file of two pictures. Over time, this may be increased as the student begins to show better comprehension of what the pictures represent. These pictures initially will be for "water play, rough house, bubbles, snack." If at any point in time, the student cannot have one of the activities, (e.g., it's raining outside, so no water play), then that picture should not be in her activity choice book.

On the student's daily schedule, pictures of the activity choice book should appear a minimum of 2-3 times per shift. When this picture appears, the student should be assisted in getting her book and shown the pictures inside the book. Watch for any signs that the student is indicating a choice of one of the activities (e.g., eye gaze at picture, touches picture, says name of item). If she does this, say, "Oh, (student's name) wants_____" and provide a prompt to get her to hand the picture to staff. Staff should then immediately allow the student to engage in that activity. If the student does not make a choice, try presenting other pictures if possible, as perhaps she does not want

either activity. If she still does not make a choice, staff can make a choice for her, prompt her to hand the picture, and then tell her, "We're going to _____now."

If at any point in time, the student initiates getting her book and handing staff a picture, if at all possible, staff should allow her to engage in the activity, even briefly, as she will then learn the "power" the pictures and her choicemaking have.

Staff should avoid using verbal prompts such as "Show me what you want" or "Give me the picture" as then the student may become dependent on these prompts and may be less likely to initiate getting a picture on her own.

Lesson Plan #6

Objective: It is important to begin to give the student ways to impact on his environment through positive and more conventional means. The student has demonstrated some understanding of photographs and magazine pictures. The purpose of this goal is to allow the student o indicate what he would like for snack through pictorial means.

Materials: Pictures of snack items

Procedure: At snack time, staff should make a few snack and beverage items available to the student (between two-four pictures). Staff should locate pictures (either photograph or large magazine cut-out pictures) which specifically match the available snack items. Initially, these pictures should be placed several inches in front of the actual snack items. (The pictures should be within the student's reach with the actual snack items behind the pictures out of the student's reach). If the student spontaneously touches a snack picture (either accidentally or with intent) staff should reward him with that snack item, and give him a verbal reinforcer such as, "Good, you touched the chips picture to tell me you wanted chips." If the student does not touch a picture, but appears to indicate a snack preference through another means, (e.g. looking intently at an item, grabbing for an item), staff should provide a non-verbal prompt which is the least intrusive possible but ensures that the student touches the snack picture. Do not use verbal prompts

such as "Show me what you want," or "Touch the picture," as it is possible that the student could become verbally prompt dependent on these cues. After the student has touched the picture (even though a prompt was needed), he should immediately be given that snack item.

NOTE: It is important to give the student up to 60 seconds to process the pictures and attempt to make a choice before prompting him.

Lesson Plan #7

Objective: At this point in time, student has exhibited a variety of unconventional ways to end a task (e.g., pulling someone's hair, throwing item, etc...) The purpose of this procedure is to provide the student with a more appropriate means to end a task.

Materials: Stop sign

Procedure: During any activity, the student will have a large red stop sign placed near her. When it becomes apparent that the student may want to end the activity, staff should provide a prompt that will ensure that the student touches the stop sign, and then, the activity should immediately be terminated. This prompt should be faded over time. If the student uses one of her unconventional behaviors to end the task, staff should tell her in a non-punitive manner, "No." Staff should then wait 5-10 seconds and bring the student back to the task and provide a prompt that will ensure that she touches the stop sign. After every successful touch of the stop sign, prompted or unprompted, the student should be given verbal praise, or other natural reinforcers.

If staff appears to have "guessed wrong," in assuming the student wanted to end a task, wait several seconds and then present her with the picture of the just completed task and the upcoming task from her schedule board, and allow her to indicate if she still wanted to continue with the task.

If staff initiates the end of an activity with the student, again the

stop sign should be used. Staff should touch the stop sign and tell the student, "___(e.g., lunch) is all done."

Because it is important that this program be consistently carried out across activities for the student to "get the idea" of the stop sign, staff working with the student must remember to carry a stop sign with them into the community and throughout the facility.

Chapter 3

Choices: The Next Step

A Model For Choice-Making [8]

I.	***Determine the primary mode and level of expressive and receptive communication used by the individual.***
II.	***Define the problem.***
III.	***Using the individual's pre-determined communication mode, determine <u>options</u> available to individual.***
IV.	***Evaluate the options:***
V.	***Select an option (positively reinforce the process of selection).***
VI.	***Develop a "plan of action".***
VII.	***Experience outcome.***
VIII.	***Examine the experience.***

[8]Developed by the Choices Committee of Little Friends, Inc., Naperville, Illinois. 1992

Choices - The Next Step

In the previous chapter, we discussed issues surrounding the basics of choice-making: expressing preferences, understanding that one's actions can have predictable outcomes, and learning to take advantage of simple options in daily activities. For some of the people we support, these steps in learning choice-making will be the primary areas in which training will focus. Others need support in making the more complex and far-ranging decisions that all adults face: choices about career, personal relationships, living arrangements, etc. This chapter presents a model of the choice-making process which can be used to structure training on making these more involved decisions. The model may be used in its entirety, as applied to a given choice-making situation, or parts may be excerpted to provide training on a specific part of the process that may be difficult for the person.

I. Determine the primary mode and level of expressive and receptive communication used by the individual.

The first step in the process is assessment of communication. As discussed in the preceding chapter, it is important to know the person's receptive and expressive abilities, and to use communication modalities that are functional for the person.

II. Define the problem.

The second step is definition of the problem. This could involve putting the problem in the form of a question: for instance, "Should I take a job at Wendy's?"

III. Using the individual's pre-determined communication mode, determine <u>options</u> available to individual.

Once the problem is defined, the next step is outlining available options. These should be relevant to the situation and realistic. The individual may need assistance in generating these options. Options in the given example might be: working at Wendy's part-time; working at Wendy's full-time; not working at Wendy's at all; working at a different job. This step of the choice-making process may be one that could be a focus of training in various choice-making situations; for example, the person could have a goal of learning to identify situations that require decisions and generating options by practicing this in a variety of contexts.

IV. Evaluate the options:

Evaluating the options of a choice is a complex process. Here, staff may need to "play detective" in order to find out what the individual's experiences in relation to the situation have been. This can involve questioning the person, observing their behavior with regard to

the situation, interviewing others who know the person well, and reviewing their records. This process may reveal significant information about the person's reasons for approaching the situation the way they do. For instance, in the given example, it may turn out that the person has a favorite sibling who works at Wendy's, or that they love to eat at Wendy's.

Similarly, it is helpful to know the person's level of exposure to the situation: Have they been to Wendy's? Do they know what someone who works there would do at their job? If the person's level of exposure to the situation is minimal, it may be that the most important step in the choice-making process is to provide them with a chance to experience the situation - for instance, to actually see what's involved in working at Wendy's.

At this step of the process, it is necessary to evaluate whether the situation is one that can be safely experienced by the person. If the situation is one which could endanger the person's life or safety, or one which could pose a threat to someone else's life or safety, then steps need to be taken to protect the individual or others involved. Sometimes it is impossible to prevent the person from going ahead with their decision, but it is at least possible to provide them or others with information that can protect them.

If the person has a guardian, this is a point at which the guardian obviously needs to be involved and informed. If the person does not have a guardian, but is contemplating a decision which might significantly endanger him or her or others, then it may be necessary to initiate proceedings to have a guardian appointed. This decision should

not be made lightly, but neither should the individual be allowed to take reckless actions in the name of choice.

A. Identify the skills necessary to act on the option.

Once the options and level of exposure to the situation have been identified, the question of skills should be addressed. Does the person have the skills they need to act on the identified options? For instance, if the person is thinking of a job at Wendy's, do they have the physical strength and capabilities necessary to carry out the job duties? Do they have the self-care skills necessary to maintain an acceptable level of grooming and hygiene? Do they have sufficient communication skills to function in the work environment? These questions should be seen not as justifications for opposing the choice, but rather as signposts indicating directions for training. Staff should be realistic, but avoid the tendency towards "ready for" thinking: John is not "ready for" a job at Wendy's because he doesn't wash his hands well, etc. It may be necessary to help the person see the connection between skills and the ability to carry out a given option --- in other words, to help John understand why handwashing is an important skill to have in order to work in a fast food restaurant.

B. Determine the resources necessary to act on the option. (Monetary, emotional, physical, etc.)

The person should also be given assistance in determining the

resources necessary to enact their options. This could include personal resources, such as physical capabilities, or material resources such as money or transportation. Again, staff should take a constructive approach rather than using this as a way to dismiss options. If someone doesn't currently have access to transportation to Wendy's, can transportation be found? Sometimes an individual may identify an option that is unrealistic because of resource limitations and may need a more concrete presentation of this information in order to understand it. For instance, if someone wants to live in a luxury condominium but is only making $4.50 per hour, they may need a graphic presentation of how much the condominium costs compared with their available funds.

C. Determine the possible consequences of the option.

Determining the possible consequences of the available options may be difficult for many of the people we support. This requires an ability to reason abstractly and to imagine various eventualities that are not yet experienced. Even if the person can project various outcomes, they may not be able to truly perceive the impact of them without having experienced them. Here staff must provide guidance and also assume some responsibility for preventing potentially disastrous outcomes.

V. Select an option (positively reinforce the process of selection).

Having identified the person's realistic options and what is necessary to carry them out, they should be assisted in selecting an option. The process of selection needs to be reinforced: the person needs concrete feedback on the fact that they have chosen a specific option and should be encouraged to feel good about having made a choice.

VI. Develop a "plan of action"

The next step in the process is to develop a plan of action. This may involve skill training or accessing resources necessary to enact the choice. Again, this step of the process may be one which the individual can be trained to apply to various choice-making situations.

VII. Experience outcome

The individual must be given the opportunity to actually experience his choice as selected. This step must occur even if the instructor knows that the individual will not enjoy and in fact does not prefer the object or activity selected.

VIII. Examine the experience

The individual should then experience the outcome of his or her choice and participate in evaluating it. Once the choice has been made, it is crucially important to let the person experience the outcome, even if the outcome is somewhat less than desirable. For instance, if the person decides to work at Wendy's part-time, they need to be allowed to do so, even if the experience turns out to be disappointing. It is only through experiencing the outcome of one's choices that one learns to make good decisions. Here, evaluation is an important follow-up step: the person should actively participate in identifying what was good about the choice and what was bad. It may be that by making the choice, the original goal was not met. Perhaps the person had originally wanted to work at Wendy's because they thought they would have enough money to afford an apartment, but found this wasn't the case. There may be other reasons that the decision turned out to be a good one - such as making new friends at the job. If the outcome of the choice was clearly undesirable, the person should immediately be given assistance in selecting a different option.

If this model of choice-making is being applied to a more immediate set of circumstances -- for instance, to a decision of what to do next in one's schedule rather than to a decision of what to do in one's career -- the person may be taught to use self-relaxation techniques to cope with frustration if the option they select is less than satisfying.

This process can be repeated with various options until the person is able to arrive at a choice that is satisfactory.

Informed Choice

The final goal of all choice-making training is to have the individuals be able to make truly informed choices -- choices based upon actual preferences developed through sound information and experiences interacting with the natural environment. Not all individuals with developmental disabilities will achieve this goal, but all should be afforded the opportunity to develop their choice-making skills to their fullest degree.

In order to ensure informed choice, there are two important considerations: first, what information is necessary in order for the person to make a sound decision? Second, how can we make sure that the person truly understands the information given them?

The first point is largely addressed through the choice-making model presented above. Before making a decision, the individual must know what their options are, what resources will be necessary to carry out the various options, and what the potential outcome of each option might be. The latter may be the most difficult information to provide, since it is impossible to project all the ramifications of any decision. It may help to at least outline the most likely consequences, as well as the best-case and worst-case scenarios.

Persons we support may have a hard time conceptualizing the outcomes of their decisions in the abstract. This poses a problem with regard to informed choice, because simply telling someone that their actions could have a particular outcome may not ensure that they really understand the information. For instance, a person might be verbally

informed that by discontinuing their antipsychotic medication, they run the risk of deteriorating behaviorally and being hospitalized in a state-operated facility, but this might not be meaningful to them unless they have a chance to actually see the inside of the facility. Simliarly, a person who said she wanted to have a baby might be told about the responsibilities of parenthood but not actually understand what it would be like to assume these responsiblities.

To ensure truly informed choice, information should be presented in a manner that is as comprehensible to the person as possible. This may mean putting information into simpler terms or providing graphic representations (pictures, video, etc.) It may also involve having the person discuss the potential outcome with someone who has had a similar experience: for instance, talking to someone who has their own apartment, or to someone who has taken a particular sort of job, etc. It may also require enabling the person to have some direct experience of the potential outcome.

When someone is contemplating a decision that may have a harmful outcome, and personnel are unconvinced, after making their best efforts to inform the person, that he or she understands the significance of the potential outcome, difficult decisions need to be made. It may be appropriate, for instance, to contact a non-custodial relative who might be able to persuade the person to make a safer choice. It may also be necessary to inform others who might be harmed by the decision of what the person is contemplating. If the potential outcome of the decision is very seriously harmful to the person's safety or wellbeing, the issue of guardianship may need to be addressed: should

someone be asked to begin to the process of assuming decision-making power for the person?

In most issues of informed choice, support staff can inform and persuade, but cannot and should not enforce a decision. For instance, if someone wants to move in with a room-mate whom staff feel would be incompatible with them, it would be appropriate to talk with both parties about their differing habits and preferences, to point out possible points of conflict, or to set up trial visits so that each could "preview" the experience without making a commitment to the arrangement. But ultimately, staff should not, unless there is a clear need to protect the safety of one or both of the persons, prohibit the decision simply because they feel it is not the best option.

To adopt the philosophy that staff will uphold individuals' right to make their own informed choices requires that staff be able to tolerate a certain amount of failure on the part of the people they support. It is undoubtedly difficult to watch someone make a choice that we are sure will have a poor outcome, but sometimes this is necessary in order for the people we support to learn personal responsibility.

Case Study

Greg and Dave live in an apartment together. They first met about three years ago when they both lived in the same residential training program. Greg moved to the facility following his graduation from high school. Although he was developmentally disabled, Greg was excited to enter the training program that would prepare him to be more independent. His goal was to live on his own like his older brother John.

From the first, Greg and Dave seemed to hit it off. They both enjoyed the same activities - bowling, baseball, and movies - and they were both the same age. They became good friends and spent much of their free time together.

Although there were similarities in their behaviors, Greg and Dave differed in several significant ways. Greg is less independent than Dave and he relies upon others to help him determine what to do to fill free time. Dave is more independent and, at times, a bit of a loner who values his time alone from others to enjoy solitary activities. Greg's family has always been more protective and they play a big role in his life. Dave's parents are retired and live in another state. He sees them only for the major holidays. Greg has fewer functional academic skills and requires more support than Dave in the areas of budgeting and banking skills. Greg's father is the payee for his Social Security benefits.

Despite their differences, Greg and Dave made a decision to live together and receive CILA support services when the opportunity

presented itself. Together Greg and Dave worked with a counselor to determine where they wanted to live and what they could afford. Though hesitant about the change, Greg's family supported his move to an apartment. The staff felt that Greg and Dave may have some adjustment problems due to their different expectations for community living.

At first, everything went fine. Both young men worked hard to adjust to the new community. There was a new bank, a new grocery store, and a new cleaners. There were so many choices to be made that, at times, the process seemed overwhelming. Time went on and there began to be a few problems for the roommates. Greg became anxious and asked to see the social worker to discuss his concerns.

During their sessions, Greg told the counselor that he was unhappy when Dave left the apartment without him. He did not like when Dave went into his room and left him alone. Greg felt that Dave should include him in all activities.

In addition, Greg felt that Dave did not do his share of the housework. Greg's mother visited the apartment on several occasions and found things to be "a mess". Greg was sensitive to her criticisms and thought that Dave should help him clean better so that his mother would not be angry when she visited.

The counselor decided to meet with Dave. During their sessions, Dave indicated that he was unhappy with Greg as a roommate because he never left Dave alone. Dave felt that he had no privacy. He did not like Greg's mother "butting in". If things did not change, Dave wanted to move.

It was clear that the two men were not communicating very well, and that they needed to learn to see how the choices they were making each day effected the other person. The Case Worker scheduled times to meet with them individually, and together to work on the problems. Issues to be resolved included scheduling of household cleaning, scheduling recreational activities together, scheduling recreational activities for Greg which did not include Dave, assertiveness training for Greg and Dave to help them better communicate their needs. The counselor helped the men to review the options which were available to them and to determine the consequences of each option.

In addition, the social worker met with Greg's family to discuss the transition to apartment living, and the need to allow the men to determine their own standards for cleanliness, etc. She asked that all concerns be addressed to the Case Worker who could discuss the issues without having the men feel that Greg's mother was interfering in their lives.

Choice-Making Model Worksheet

1. Determine the primary mode of communication (both expressive and receptive).

   A. Talk with the individual to determine whether he/she communicates verbally.

   B. If the individual communicates effectively through verbal means then go to D.

   C. If the individual does not effectively communicate verbally, use an appropriate evaluation tool to assess how the individual most effectively communicates. (See Section #3 - Assessments of Communication skills).

      Indicate the assessment tool used

      _____

   D. Check the line which describes this individual's primary mode of communication.

      _____ Verbal

      _____ Models or actual items

      _____ Photographs

      _____ Detailed line drawings

      _____ Simple line drawings

      _____ Other (please describe)

      _____

Remember to present the following information to the individual through whatever mode of communication is most appropriate for him/her.

II. Define the problem to be resolved. What is this person making a choice about?

_____

_____

III. List the options indicated by the individual. If the individual is having trouble generating options, you may help him or her generate at least three. If it is more appropriate for you to generate the options independent of this individual, indicate this and list at least three options.

___ Options were generated entirely by this individual

___ Options were arrived at cooperatively with instructor and individual

___ Options were generated by instructor with individual present

___ Options were generated by instructor and presented to individual later

List of Options:

_____

_____

IV. Select an option

A. What is this individual's level of exposure to the problem being addressed?

_____

B. What is this individual's level of exposure to the options generated?

_____

C. How was the above information assessed? (i.e., interview with individual, observation, interview with parents, interview with staff, review of file, other)

_____

_____

D. Is the level of exposure sufficient to allow this individual to continue? (i.e., can this individual make a choice based on exposure at this point? Can you provide additional information to make the level of exposure sufficient? Should you adapt the situation in some way, or should you prevent this individual from choosing a particular option)? Describe below. Include a description of the level and type of support you will provide for each option this individual might choose.

_____

_____

E. What skills and/or resources are needed to follow through with each option? Does this individual have the skills/resources at his/her disposal? Can you adapt the situation or assist this individual so that he/she can choose any option? If not, are there options which should be discouraged or disallowed? Describe below.

_____

_____

F. Consider the likely consequence for each option. Is this individual aware of the potential consequence? Is this individual able to handle the negative (or positive) consequence when it occurs? Will you adapt the situation or intervene in some way to assist this person with the likely consequence? Describe below.

_____

_____

V. Develop a Plan of Action

A. Use the information from above to design a plan which will most effectively allow this individual to make an informed choice. Describe this plan below.

_____

_____

VI. Select an Option

A. Indicate which option this individual chose.

_____

_____

VII. Experience the Outcome

A. Describe the outcome/consequences. Was this what you (staff) expected? Was this what this individual expected? Did you provide support? If yes, describe.

_____

_____

VIII. Examine the Experience

A. Summarize the process. Indicate the option chosen. Was the outcome the same as what was expected?

_____

_____

B. Did this individual achieve his/her goal?

_____

C. If the individual did not achieve his/her initial goal, was the experience acceptable? Is the individual disappointed with the outcome? Describe the experience.

_____

D. Summary. Do you need or are you able to allow the individual to choose a different option? If the experience was negative and another option cannot be immediately presented, is there a way to make the experience less unpleasant?

_____

E. If the experience was positive, either expected or unexpected, summarize. What will the individual do in the future if faced with a similar problem?

_____

F. Note any other relevant information:

_____

Chapter 4

Choices in Residential Settings

Choices in Residential Settings [9]

That a person with developmental disabilities should be offered a choice in the place he lives, has been well documented - if not well implemented - by state policy and individual agency procedures. No more fundamental choice impacts the life of a person than where and with whom he lives.

For a person with a developmental disability the choice of where he will live will determine the freedoms and choices that will be available to him for years to come. If the person lives in a large intermediate care facility his choices about such things as when to eat, what to eat, when to bathe or shower, etc. may be severely limited due to licensing regulations and standards. If that same individual resides in a CSLA or CILA funded placement he will have many choices available to him in all aspects of daily life. He will be able to choose where he lives, and with whom he lives. ("Your Place or Mine?", A Handbook for Home Ownership[10] is a curriculum specifically developed to assist persons with disabilities to make the choices about their housing options.)

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[9]Information contained in the chapter is based upon information presented by Kathleen Carmody, Director of the Choice and Integration Project; Vic Morris, MSW, Program Development Specialist for SASED; and Nan Negri, Ph.D., Consultant on Autism.

[10]Bob Laux and Cynthia Moran-Laux, "Your Place or Mine?" A Handbook for Home Ownership (Porstmouth, NJ: Creative Management Associates, 1991) Funding provided by the Illinois Planning Council on Developmental Disabilities.

But no matter where the individual resides, the residential provider has the ability to provide opportunities for choice to the individuals served. Providing choice, as mentioned earlier, is interconnected with values - the agency's values, and the staff's values. Offering choices to an individual gives them dignity. The person is recognized as having competencies and worth. You cannot offer a choice to an individual without realizing their humanity, because in offering the choice you must acknowledge that person and his rights to having a voice and some degree of control in his life.

Daily Schedules

In a residential setting choice opportunities begin with the daily schedule of activities. If the schedule provides no opportunity for flexibility by the resident, then choice opportunities are minimized. However, even individuals who require highly structured programming can be offered choices as part of that structure. For example, a child with autism who resides in a group home may need to complete his grooming tasks each morning between 7:00-7:30 AM in order to be on time for the school bus. A checklist may be used to monitor his success at each task, but that does not preclude the Instructor from allowing the child to determine the order in which he will complete the required tasks.

In a small group setting such as a CRA, opportunities for choice can routinely be offered throughout the day. The residents can be offered choice in selecting their clothing for the day. If the individual does not have the skills required to select clothing which is proper for the event, or for the weather, then he can be offered choices between two or more acceptable alternatives. As with all aspects of choice, the course of instruction is to move from having the individual develop preferences to having the individuals make truly informed choices.

The following is a list of some activities which are available in residential settings and which should be a part of the residential program routine to maximize the individual's opportunities for developing skills in choosing.

Personal Care Skills

- *Choice of hairstyle.*
- *Choice of when to get hair cut or styled.*
- *Choice of where to get your hair cut.*
- *Choice of shoe style.*
- *Choice of clothing.*
- *Choice of personal care items - brands, colors, etc.*
- *Choice of where to purchase clothing.*

Daily routine

- *Choice of when to eat meals.*
- *Choice of what to eat at meals.*
- *Choice not to eat a given meal.*
- *Choice to follow specific religious menu.*
- *Choice of people with whom you eat.*
- *Choice of when to take a bath or shower.*
- *Choice of when to get up or go to sleep.*
- *Choice of when you may leave the home.*
- *Choice of when to clean your room.*
- *Choice of when to go shopping for personal items.*
- *Choice of when you attend church services.*
- *Choice of which church services you attend.*

Home Environment

- *Choice of bedroom.*
- *Choice of roommate.*
- *Choice of place to sit at dinner table.*
- *Choice of where to enjoy leisure time in the home.*
- *Choice of furnishings.*
- *Choice of room decor, including bedspreads, etc.*

Recreation and Leisure

- *Choice of what you can do with free time.*
- *Choice of when to watch TV.*
- *Choice of what you watch when viewing TV.*
- *Choice of when you listen to the radio.*
- *Choice of what station you listen to on the radio.*
- *Choice of attending event others may not like.*
- *Choice of with whom you spend your free time.*

The LIFESTYLE OPPORTUNITIES inventory at the end of this chapter which was prepared by Kathleen Carmody, Director of the Choice and Integration project, surveys a wide range of opportunities for choice-making which should be available to every individual.

Before the residents are taught to "make choices", the staff must be committed to offering opportunities for choice-making throughout the day. For many of the individuals served in residential programs the issue is not teaching them to make choices, but to teach the staff to respect the choices the resident has made, even when the staff member does not agree with the choice. This requires that the staff remove themselves from any authoritarian, parental role and fill a more supportive role. Their role is in fact to ***support*** the individual: to provide assistance and aid as necessary. With appropriate training, the staff will understand the mission of the agency and will provide ongoing opportunities for the residents to make choices throughout their day.

Individuals served in residential programs have a wide range of disabilities: mild cognitive impairments to profound disabilities. In addition, the characteristics of the environments in which they reside vary greatly; from a CILA apartment to a State Operated Facility. The choice-making opportunities change in each of these settings.

John resides in an apartment and receives CILA services. He receives support services daily from his Case Worker. With the assistance of his staff, John participates in the development of the weekly menu. He will do his own grocery shopping and his own cooking. He will pay his rent and monthly utility bills. He will launder his own clothing. Each day presents hundreds of opportunities to learn skills of daily living in a natural environment. His opportunities for choice-making are ongoing and almost cannot be avoided. The members of the Community Support Team have no difficulty in finding methods to introduce meaningful choices into John's life.

Mary is severely mentally retarded and has physical disabilities as well. Mary resides in a group home, which is licensed as a CRA, with six other women . The staff at the group home prepare the meals for the women. The dietician prepares the menus to insure that everyone receives a balanced diet. Mary's father is the payee for her Social Security and Supplemental Security benefits. Mary receives $30 a month to cover her personal expenses. Mary never sees a utility bill or a rent bill. Mary's environment does not afford her as many opportunities for choice making. The structure of her day limits her ability to make choices about a wide range of issues. The staff who work with Mary have a more difficult time finding choice-making

opportunities which are meaningful for Mary because she has little control over her life. The schedule of the day is set around the needs of all six women and the staff.

Lifestyle Opportunities [11]

In Your Home:

- What time do you get up in the morning, what time would you like to get up in the morning
- What time do you go to bed at night, what time would you like to go to bed at night
- Do you like to decide when you'll get up in the morning and go to bed at night
- Do you like to decide what you'll eat for meals
- Would you like to help prepare your own meals
- Do you like to choose when you'll eat meals
- Would you like to be able to invite family and friends to your home for a private meal
- Do you like to watch television
- Do you get to pick out what you watch on television
- Can you watch television when you want
- Can you watch television in the room you want
- How many people would you like to share your bathroom/bathtub/shower
- How many people would you like to share your bedroom/bathtub/shower
- How many people would you like to share your bedroom
- Would you like to choose with whom you shared a bedroom
- Would you like to help choose the other people with whom you live
- Would you like to help choose the staff who help you in your home
- Would you like to be able to tell the staff what they are doing well and what they could do better
- Would you like to be able to make telephone calls without having to use a pay phone
- Would you like to be able to talk to people on the telephone in private

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[11]Developed by Kathleen Carmody, Director, Choice and Integration Project.

Lifestyle Opportunities [12]

In Your Neighborhood:

- ? What would you like to do during the day, where would you like to go during the day
- ? What would you like to do during the evening, where would you like to go during the evening
- ? What would you like to do on the weekend, where would you like to go on the weekend
- ? Would you like to do your own grocery shopping
- ? Would you like to go to the barber/beauty shop to have your hair cut
- ? Would you like to go out to eat at restaurants
- ? Would you like to live near families with children
- ? Would you like to live near other single people
- ? Would you like to live near other people with disabilities
- ? Would you like to live in the same neighborhood as you live now
- ? What is most important to you about the neighborhood in which you live
- ? What is least important to you about the neighborhood in which you live
- ? Is church important to you
- ? Would you like to be able to attend mass at a church in your neighborhood
- ? Would you like to visit different churches and choose which one you'd like to attend
- ? Would you like to attend social and recreational gatherings at a church
- ? Do you like to go shopping

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[12]Developed by Kathleen Carmody, Director, Choice and Integration Project.

Lifestyle Opportunities [13]

With Your Friends:

- ? Do you have friends at the nursing home, who are they
- ? Do you have friends at your day program, who are they
- ? What do you like to do with your friends
- ? Do you have enough friends
- ? Would you like to make new friends
- ? Would you like to live with any of your friends
- ? Would you like to have someone drive you or teach you to take the bus so you can visit your friends

By Yourself:

- ? Do you like to choose what clothes you'll wear each day
- ? Do you like to be able to keep personal items in your room
- ? Would you like to have a job and earn money
- ? What kind of a job do you think you would like to have
- ? Do you like to have a place in your home where you can be by yourself

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[13]Developed by Kathleen Carmody, Director, Choice and Integration Project.

Opportunities To Make Choices [14]

- ? Will the person stay where they are at or will they move
- ? Will the person move to a facility/institution/house/apartment
- ? Where will the person live
- ? Which agency(s) will provide services to the person
- ? Will the home be single-sex or co-ed
- ? Will the people have chosen to live together
- ? Will the people have met each other before they live together
- ? How will the home be furnished/decorated
- ? Who will select the furnishings/decorations
- ? How will the home be maintained
- ? Which staff will provide services within the home
- ? How will staff be selected
- ? Will people living in the home evaluate staff's performance
- ? What types of staff training will be conducted
- ? When will the move occur
- ? Will the person be involved in a day program
- ? Who will select what day time activity the person will attend
- ? What areas and skills will be addressed by formal programming
- ? Who will decide what the goals and objectives will be
- ? Will the person be given the opportunity to earn a meaningful income
- ? How will free time be spent
- ? How much free time will there be and when will it occur
- ? When will meals be eaten
- ? Who will plan the menu for meals
- ? Can menus be changed at the last minute
- ? When will shopping be done and who will do it
- ? Which chores will be done and when must they be done
- ? How will opportunities to participate in community activities be explored and pursued

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[14]Developed by Kathleen Carmody, Director, Choice and Integration Project.

Opportunities To Make Choices

- ? Will group activities be scheduled during leisure time, who will select and plan these activities
- ? Can a person decline to participate in group activities
- ? Will people receive necessary staff support to pursue hobbies and interests
- ? Are individualized educational, civic and/or religious opportunities available

Case Study

Sarah is a thirty-five year old woman who has lived in a Community Living Facility (CLF) for the past six years. She has multiple disabilities including a severe visual impairment, moderate mental retardation, and a speech problem.

Sarah has achieved many skills during the last six years. She is capable of caring for her personal needs, has good housekeeping skills, and fairly good money management skills. During her futures planning process, Sarah stated that she would like to move to an apartment setting through the CILA program. Sarah made an application for CILA but as funding is currently not available to make this transition, the staff at the CLF have revised Sarah's service plan to increase her independence and self-reliance.

The major focus of the change in the service plan for Sarah is to allow Sarah more control over her daily and weekly schedule -with the final goal being Sarah having total control of her schedule. With Sarah having more control over her daily activities, she will have more responsibility for the outcomes of the choice she makes throughout each day. This is a life style which more closely matches the CILA environment which Sarah hopes to live in as soon as possible.

The first step in the process is to outline, once each week, Sarah's personal responsibilities (i.e., laundry, grocery shopping, room cleaning, dental appointment, work, counseling sessions, etc.) Sarah works with her support staff to fill in a rough schedule of when she will accomplish

each of these tasks. Sarah may complete the items sooner than listed on the schedule, but not later than the date and time agreed upon.

The staff will assist with any conflicts which may be in the schedule. Sarah has a very full and active personal life and her desires may, at times, conflict with the ability to provide her the assistance she requires. For example, Sarah needs transportation assistance to the laundromat due to the severity of her visual impairment. If the support staff are unable to provide transportation when requested, a compromise schedule will be developed to meet everyone's needs.

When Sarah does not complete activities as indicated by her schedule, the staff will allow the natural consequence of that decision to occur. In this way Sarah will learn that if she does not complete necessary tasks, her life will be impacted in some meaningful way; for example, if she doesn't complete the laundry when required, she may not have clean clothes for her date on Friday night. As Sarah shows success in her ability to self-schedule her activities, she will be given more and more control over the amount of the day she schedules.

Chapter 5

Choices in a Vocational Setting

Choices in a Vocational Setting

Training in choice-making in the vocational area can take many forms, depending on the learner's capabilities and setting. Choice-making can be integrated throughout the activities of a sheltered setting, or can take the form of assisting individuals in making more long-range career decisions.

In Developmental Training

In a sheltered setting such as a Developmental Training or Special Education classroom, staff can work on choice training using the techniques described in chapter two, "Choices - Where to Begin." Individuals who are not yet engaged in actual paid work activities can work on learning to use an object or picture schedule to make choices about activities in the classroom. In a group setting such as this, a picture schedule can be posted for the benefit of the entire classroom. Similarly, posted activity choice cards can be made available to the individuals in the room to encourage them to express wants and needs throughout the day. As discussed previously, the skill of communicating a desire to end or leave an activity is as important as the skill of expressing a preference for an activity, and this can be worked on with individuals in the Developmental Training classroom as well.

In Sheltered Work Settings

For persons engaged in paid work in a sheltered setting, choice-making can be incorporated into the daily schedule as well. For instance, someone can choose when they will take their break, with whom they will eat lunch, or possibly which tasks they will work on. Often, the provision of structured choice-making opportunities is an important component of behavior management in the sheltered setting, since it affords the individual a degree of control and autonomy which may otherwise be missing in such a highly controlled setting.

In sheltered work settings, there is often a conflict between the perceived goal of teaching individuals the importance of respecting supervisory authority (i.e., work rules or employer's standards of behavior) and encouraging autonomy. Staff need to remember that while it is important to teach workers how to comply with supervisory directives and company policies, it is also important to teach them how to assertively express their concerns and resolve problems. Workers should be taught how to use an established grievance procedure, and encouraged to take their concerns through proper channels. Concerns thus expressed should be taken seriously and addressed as legitimate issues for discussion. This allows the person to learn the skills they need to negotiate such situations in "real world" work settings.

Employee Management Committee

Another mechanism for teaching sheltered employees to be self-

determining is the Employee Management Committee. This is a committee, formed of elected representatives of the workforce, whose role is to bring up employee concerns and suggestions to the management of the workshop. Staff should be involved in the committee to help members identify their concerns and formulate their requests or questions to the workshop administration, but care should be taken that the committee members are encouraged to take as active a role as possible. Again, the committee's concerns should be taken seriously and addressed through a structured process by management, with clear feedback given on questions the committee raises and reasons for management decisions.

On-Site Job Evaluations

An important area for vocational choice-making comes in the transition between sheltered and community employment. There is much that can be done within the sheltered setting to enhance the opportunity for informed career choices. First of all, evaluations conducted preparatory to finding community employment should involve as much experience of actual community work situations as possible. Rather than trying to make decisions about jobs based solely on a person's performance within the workshop on subcontract jobs or work samples, the evaluation process should strive for job-site evaluations in the community wherever possible. This can be arranged through existing supported employment sites or with community employers who are supportive of the agency. The individual can be offered a chance to

try out a job on a temporary, part-time basis, with the agency paying their wages, under the supervision of an evaluator. This exposure to actual work experiences is extraordinarily valuable in helping both staff and the individual to assess vocational options and their appropriateness for the person.

Another mechanism to broaden the individual's exposure to community work experiences is to have participation in groups that visit community job sites and discuss various career options. Staff can take groups of workers who are at the point of considering community jobs into different places of employment so they can see firsthand the activities of workers in those settings. Individuals who have already obtained community employment can act as guest speakers, answering questions about their jobs and telling the group about the good and bad aspects of various types of work.

Community-based Employment

The model of choice-making presented in chapter three "Choices - The Next Step" can be used to good advantage in the process of selecting a job in the community. Careful assessment should be done of the person's preferences and abilities, and an effort should be made to match the person with a job that satisfies their stated preferences. Individuals will vary considerably with regard to the components of the process that are most important; for some, resources will be a predominant question -- for instance, their physical capabilities to perform various jobs, or their ability to find transportation to the job

site. For others, there may be distinct preferences with regard to the type of work obtained that will need to be met in order for the experience to be satisfactory -- for instance, someone who strongly prefers to work in an office setting rather than an industrial or service industry setting.

The individual may need assistance in identifying what components of a job are most important to them and in making realistic judgements of what their resources are. Sometimes it may be necessary for someone to experience a less-than-desirable outcome in a community job before they are able to realize that a particular option is unrealistic. Although every effort should be made to maximize a person's chances of success in a community job, failures should not be regarded as finalities -- after all, how many of us have tried a variety of jobs before finding one that is satisfying long-term?

If an agency is to encourage choice-making in the vocational area, it is important to realize that individuals may make choices that require changes in the way we typically offer support services. For instance, someone may identify, as ideal, a job option which requires that support services be provided at unusual hours; or, a person may choose to work a schedule that causes inconvenience for the residential program. Although there are always limitations to what an agency can provide in the way of support services, it is important to be flexible and to try to assist the person in carrying out their preferred vocational option even if it requires changing some typical patterns of service provision.

Once a person has obtained a community job, they may still require support in using their choice-making skills at the job. For

instance, they may need training in how to assertively handle conflicts at the job, or support in making decisions about taking on new duties. As always, staff must be ready to help the person obtain the necessary skills and information for making the best decision while resisting the temptation to step in and decide for the person. When failures occur, these should be approached as learning experiences and fertile ground for further training.

Lifestyle Opportunities [15]

At Work:

? Do you have a job, or would you like to have a job.

? Do you like where you are working or would you like to work somewhere else.

? Is making a lot of money important to you.

? Is working close to where you live important to you.

? Would you like to work around other people or by yourself.

? Is working in a clean environment important to you.

? Would you like to dress casually for work or dress nicely.

? Would you like to wear a uniform.

? Do you want a job where you would sit most of the day.

? Do you want a job where you would stand and move around most of the day.

? Would you like to work indoors or outdoors.

? Would you like to work with animals.

? Would you like to work with children.

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[15]Developed by Kathleen Carmody, Director, Choice and Integration Project.

Client: _____ Date: _____

SPECTRUM VOCATIONAL SERVICES
Supported Employment Program
Job Match Form

	Client Choice		Job Obtained
1.	Hours client can work: _____	1.	Working hours of the job: _____
2.	Client's ability to transport: _____	2.	Transportation to job: _____
3.	Social environment client prefers (i.e., many people vs. few, large vs. small, etc.) _____ _____ _____	3.	Social environment: _____ _____ _____ _____ _____
4.	Environmental conditions client prefers: _____ _____	4.	Environmental conditions of the job: _____ _____ _____ _____
5.	Client's physical stamina: _____ _____	5.	Physical stamina required by job: _____ _____
6.	Client's academic achievement: (i.e., reading, writing, ability to follow directions, etc.): _____ _____ _____	6.	Academics required by job: _____ _____ _____ _____ _____

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	Client Choice		Job Obtained
7.	Supervision best suited for client: _____	7.	Degree of supervision available by job: _____
8.	Need for routine: _____	8.	Job routine: _____
9.	Public contact that is preferable (i.e., direct communication with public vs. not being responsible to interact with public: _____	9.	Necessary public contact:
10.	Job pace that is preferred:	10.	Job pace required: _____
11.	Ability to communicate (i.e., verbal vs. non-verbal, etc.) _____	11.	Communication skills necessary: _____
12.	Benefits required by client: _____	12.	Benefits available: _____
13.	Client job preferences:	13.	Type of job available:
14.	Client job skills: _____	14.	Job duties: _____

Client Choice	Job Obtained
15. Salary requirements: _____	15. Salary offered: _____
16. Insurance needs: _____	16. Insurance available: _____
17. Staff comments: _____	17. Staff comments: _____

Client Signature	Date
Completed by:	Date

18. Date of job interview: _____

19. Was client offered the job? _____

20. Did client accept the job offer? _____

21. Starting date of the job: _____

22. Job profile completed by: _____

INTERVIEWS

Client: _____ Job Developer: _____

1. Date of Interview: _____
   Location: _____
   Position: _____
   Interviewer: _____
   Outcome: _____

2. Date of Interview: _____
   Location: _____
   Position: _____
   Interviewer: _____
   Outcome: _____

3. Date of Interview: _____
   Location: _____
   Position: _____
   Interviewer: _____
   Outcome: _____

4. Date of Interview: _____
   Location: _____
   Position: _____
   Interviewer: _____
   Outcome: _____

Little Friends, Inc.

Career Plan

Name: Interviewer: _____

Address: Date: _____

Phone #:

Legal Status:

Assigned Spectrum Staff of Employee:

A. Medical Alerts:

B. Occupational Areas of Interest:

1. Factors to stay away from:

2. Possible job matches:

C. Transportation Skills and Issues:

D. Ability to Sequence Tasks:

E. Speed/Stamina:

F. Quality:

G. Intensity of Support Required:

H. Personal Appearance:

I. Social Skills:

J. Communication Skills:

K. Time Awareness (passage of time):

L. Attendance:

M. Reaction to Criticism, Problems, Change:

N. Requests Assistance:

O. Ability to Follow Checklist:

If this individual could have the perfect job, please describe what this would be (think about things like level of support anticipated, hours, number of co-workers, number of supervisors, enclave of individual placement, complexity of job or tasks, etc.).

Comments (if any):

Case Study

Situation 1:

Jim is a twenty-two year old man who has recently begun attending Developmental Training. Jim has been diagnosed as mentally retarded in the severe-profound range of functioning. He is able to approximate a few manual signs, such as "candy" and "toilet", but he does not sign fluently nor does he use speech to express his wants and needs. Sometimes Jim will lead staff to something he wants; for instance, he will pull them toward the door if he wants to leave the room.

Using the Schuler-Borman assessment method, staff are able to ascertain that Jim is able to match one object to an identical object and can sometimes match an object to a line drawing representing it. He is unable to match colored pictures or photos to objects. From the assessment, it is also clear that Jim needs gestural cues to direct his attention to the task at hand and will otherwise engage in stereotypic behaviors (flapping his hands or rocking) when presented with the objects or pictures.

In order to help Jim begin to express his preferences within the daily routine of the classroom, staff begin by using two of the line drawings Jim understands: "radio" and "book". During the afternoon, when the class typically has a period of leisure activities, the staff presented Jim with the two drawings on cards. A gestural cue was used to direct Jim's attention to the drawings. When Jim made any

movement towards one of the cards, the staff respond by saying, "Good, Jim, you chose _____ (radio or book). Let's get the _____." They then hand Jim the card and take him to the object he indicated. Jim is then given a chance to spend time listening to the radio or looking at the book.

At first, Jim did not seem to make the connection between his gesture towards one of the cards and being able to then use the object. However, after repeated trials, staff began to see that he would take initiative to indicate one of the cards by touching it without being given a gestural cue. Eventually, staff were able to develop a picture schedule for Jim, kept at his desk, with several options being offered at different points during the day. Jim could then indicate his preference of activities using the cards.

Situation 2:

Jean is a 32-year old woman who has been working in the sheltered workshop for the last six years. She lives in a CILA apartment with support from the residential staff of the agency. Jean has been diagnosed as having mental retardation at the moderate level. She communicates verbally, and is able to express her basic wants and needs effectively, but has difficulty expressing more abstract concepts. She can read at a fourth-grade level. In the workshop, Jean has been doing jobs such as light assembly, packaging and collation. She is able to perform all these jobs well, but prefers collation jobs and will ask to work on them rather than on assembly or packaging if they are available. Jean often complains that the assembly jobs, particularly one that involves parts packed in grease, make her hands dirty. She is someone who takes pride in her appearance and is always careful to wear an apron while working to protect her clothing.

Before her annual interdisciplinary staffing, staff met with Jean to discuss her goals for the coming year. When asked about the workshop, Jean says that she would rather have "an outside job". Although Jean has never worked in the community, she expresses to staff that she would like a job as a secretary.

At the staffing, Jean is referred to the Supported Employment program for evaluation. The first step is a job-site evaluation, wherein Jean is given an opportunity to work at an actual community job site (where the agency already maintains a supported employment enclave) on a short-term basis. The job sites available include a nursing home

laundry department, a fast-food restaurant, and an industrial setting. Jean is very clear about not wanting to try the industrial site, and after some discussion, selects the fast-food restaurant for her evaluation. The evaluator then spends the next two weeks at the restaurant with Jean each afternoon, introducing her to the job and assessing her performance. At the end of the evaluation, it is clear that Jean is able to learn the new job duties readily and to meet the employer's standards for behavior, dress and grooming. She enjoys interacting with customers and co-workers, who find her easy to get along with. However, she states that the job itself is not something she would want to do long-term: she doesn't care for the cleaning duties involved in the job, and doesn't like wearing the restaurant uniform.

Next, the supported employment staff meet with Jean, the residential staff who support her and her workshop supervisor to discuss what type of job would be ideal for her. Again, she states her preference to work as a secretary. The residential staff note that Jean has a typewriter in her apartment which she enjoys using, but that her typing speed is slow (about ten words per minute, with good accuracy.) Since it seems unlikely that Jean could secure a job as a secretary without having better typing skills, the staff talk with her at greater length to determine what it is about secretarial work that she finds appealing. It turns out that she likes the idea of working in an office, and of having a job where she can dress nicely. As is clear from her job-site evaluation, having people contact is an important element as well.

With this information (as well as information about Jean's resources for transportation, preferred hours, income needs, etc.) the

Job Developer in the supported employment program begins to work with Jean on identifying job openings that meet these criteria. It takes some time to find an office job that doesn't require typing skills, but eventually a position is found in an office near Jean's home which involves delivering faxes within the building. Jean is hired for the job, which she finds much more satisfying than being in the workshop. Her employer reports that she is a pleasure to have on staff because of her positive attitude.

Chapter 6

Children and Choice

Children and Choice

It is now a commonly held belief among Early Education Specialists that young children should be allowed to make choices in their daily lives. The opportunity to make choices fosters a sense of positive self worth, a sense of mastery, and a sense of being able to control some aspects of their lives. This is critical for all children whether or not they face the challenges of a developmental and/or mental disability. The value of choice-making does not end when a child ends early education and begins elementary education. Positive self esteem, a sense of a mastery, and the confidence with which to take risks continue to be desired outcomes for children and adolescents throughout the school years.

School is not often viewed as an arena for choice-making. The common public perspective is one of viewing schools as places for authoritarian figures to assist children in learning to follow certain dictates (i.e. becoming school compliant), to "do as they are told" and to "toe the line." While this is in part a reality, it becomes an administrative and professional responsibility to offer choices that are developmentally appropriate to students of all ages. What opportunities for choice-making are provided should depend on the age, abilities, and developmental stage of the child.

Choices in Elementary Schools

In elementary schools, choice-making opportunities occur daily. As an example, at the beginning of a school year children may choose their cubby, the place where they keep their personal articles. They can decorate their name plate on the cubby to provide a sense of uniqueness. Children of all ages enjoy having a say in the type of rewards they can earn for completed work, extra credit, or for exhibiting school compliant behaviors. Children can choose how they spend their recess or break times. While one child may prefer playing a physical outdoor game, another may prefer a quieter board game. Allowing the child the choice gives him the message that he is a respected individual whose ideas and preferences are listened to, accepted, and valued. Over time the child internalizes that he, with his own brand of uniqueness, is valued.

If, by virtue of age or ability, the child does not have the skills required to make a choice which is proper to the occasion (i.e. wearing shorts in mid-winter) then more limited choices may be offered. The goal however is to progress towards opportunities to make increasingly informed choices.

In Middle School

As the maturation process proceeds, the child readies himself to cope with the increasingly sophisticated choices presented to him. In a traditional middle school there are choices to be made regarding whether or not to play a musical instrument, and if so, which one? No

longer do entire classrooms sit together in the cafeteria. Now decisions need to be made regarding specific peers to eat with. Children have choices about which after-school activities to engage in, the languages they study, and how they use their free time. They also have choices on whether to go to a particular class or not. Students, as they have less adult guidance at this point, need to be able to evaluate each option presented to them. The ability to successfully weigh the pros against the cons becomes a basic survival tool for choice-making at this stage of a child's development. Students fall on a continuum regarding this ability, but it is a fact that those who are stronger in this area become more successful in the next major education stage--high school.

In High School

In high school, the success of the educational process rests predominantly with the student. Adolescents have choices about what classes to take; how much effort to put into them; which extracurricular activities to join and then how involved in them one should be; and finally, which peers to associate with (a more complicated choice process as high schools traditionally are double or triple the size of middle schools). The list goes on. Because these choices are so basic, we do not normally attribute much significance to them.

Special Education and Choice

Those of us working with the special education sector realize that choice-making is essential and that it confronts all students daily. The manner in which choices are dealt with by the individual effects that person not only in that particular situation, but it also effects the way he views himself and others around him. It is a reality that for many special education students, choice-making is difficult and for some, seemingly impossible. This is the target population which needs adult teaching and intervention around choice-making. The better able a child or adolescent is in making informed choices, the more empowered he feels and by extension, the better he will feel about himself.

Following is a list of possible choice-making activities available in school settings. Any of these help a child discover that they can act on their world. Each successive choice builds the confidence necessary to make another and possibly more difficult or complicated choice.

Considerations In Providing Choice-Making Opportunities
Child & Adolescent Program

- Will the student have choice of seating in classroom?
- Will the student have choice of seating in lunchroom?
- Will the student have choice of free time activities?
- Can the student refuse to participate in free time activities?
- Who will decide what the goals and objectives of IEP will be?
- How will community activities be explored and pursued?
- Can student decide not to participate in a community rec-leisure activity he doesn't like?
- Does student have a choice of seating on bus/van?
- Does student have at least two choices for rewards?
- Does student have a choice of P.E. activities at gym, YMCA, health club?
- Who decides how student's money will be spent on shopping trips?
- Does student have a choice of menu items in restaurant? Or what restaurant to go to?
- May the student attend his annual review/parent conference?

- When the student reaches 18, can he sign his own release forms?
- Can the student view any part of his files?
- Is student involved in the planning of an individual behavior program?
- Who decides what task student will perform in a group life skill such as cooking or cleaning?
- Does the child prefer working alone in small groups or in large groups?
- Does the child prefer seat work or work requiring movement (blackboard, working on the floor)
- Can child choose his classroom job?
- Can child choose his academic schedule?

Case Study

Background Information

Justin is a sixteen year old young man with a diagnosis of autism. Justin currently spends half of his school day in a segregated alternative high school which serves individuals with communicative, behavior, and cognitive challenges - half of his school day at his home district high school. In this local setting, Justin participates in both a self-contained special education class and inclusion into regular education classes, including gym, lunch, and auto-mechanics.

Justin lives at home with his parents and one younger sibling. He spends two weekends a month in respite at a local group home. Justin spends a considerable amount of time in the community, and has recently begun a job for five hours per week as a dishwasher at a neighborhood restaurant.

Communication Skills

Although Justin has some verbal language, much of it is echolalic in nature. Justin has difficulty indicating yes or no through verbal means. He is also unable to indicate choice or preference when presented with a, "Do you want _____or____?" situation as he tends to repeat either both choices offered or just states the last item stated whether that is the one he wanted or not.

Transitions and changes in schedule are often difficult for Justin

to handle. Justin will use unconventional behaviors such as hitting, spitting, and kicking to communicate confusion, frustration, protest. He does not have a conventional means of indicating when he needs assistance, or wants to end or change an activity.

An assessment was completed to determine Justin's level of symbolic representation. It was determined that Justin understood line drawings for concrete items such as food, clothing, and recreation and leisure "toys," but needed photographs for other items such as specific community activities, school chores, etc...

Target Areas For Increasing Choice-making Skills

It was determined that a major area to target for Justin involved giving him more choice over when he wanted to end an activity. Frequently he would exhibit hitting or kicking if he was directed to continue to engage in an activity past his "breaking point." At his job site, Justin was given a mini-schedule for dishwashing. He was allowed to insert his break cards or lunch card into a picture schedule at points where he wanted to take a break. This mini-schedule was set up on a daily basis with Justin. For example, he had pictures of cups, plates, silverware, etc... He would then decide which item he would wash first and place that in his picture sequence. He was then given a choice of choosing either another dishwashing item or a break card. (This procedure continued until he had completed his work mini-schedule).

At school, Justin's daily activity pictures were placed on either blue or red backgrounds before they were placed into his schedule book.

Blue background activities were those which Justin had to complete per teacher's time or work requirements. Red background pictures were those which Justin could choose to end at any time. Justin was given a stop/done card whenever he was engaged in a red background activity to remind him that he could signal when he wanted to end these tasks.

Additionally, Justin had "activity choice" cards placed randomly in his daily schedule. When one of these cards came up, Justin was directed to a choice board and allowed to choose any activity pictured there for his "choice activity." A timer was used to help Justin understand when the activity would end. Additionally, a "stop/done" card was with him during choice activities so he could control whether he wanted to end it before the timer did.

Justin was frequently given choices as to whom he wanted to participate in an activity with him. For example, in his regular education auto-mechanics class, frequently the students needed to choose partners. Justin was presented with people choices through photographs and thus was able to have some control over whom he participated with in a given activity.

On a twice-weekly basis, Justin participated in community-based instruction; once at his segregated alternative high school, and once with his self-contained class at the regular education high school. Justin was provided with pictorial choices of local restaurants, and he was allowed to select where he wanted to have lunch. He was then given a "modified pictorial menu" from the restaurant and was able to choose one item from three food categories (e.g., main dish, side dish, beverage). He also was allowed to select a lunch he wanted to cook from

picture recipes and would then buy the needed ingredients for this recipe from a pictured recipe list. On occasion, Justin would pick one item, but in reality want another. For example, he might pick a cheeseburger, but then want a peer's chicken nuggets. It was critical for Justin to see the natural consequence of his choice; therefore, he was always given the item he selected. However, if this genuinely frustrated Justin, he was allowed to make a choice again.

Because Justin was unable to use his verbal language to indicate yes or no, he was presented with yes/no cards which he kept in a small plastic holder in his pocket. He was systematically taught to use these cards when asked a yes or no question. Again, it was crucial that Justin initially experience the natural consequence of his choice. Therefore, if he was asked "Do you want some Coke?", and he touched, "NO," he would not be provided with Coke. If it was obvious that in fact he did want it, several seconds later he would be re-asked the question, and staff would assist him in pointing to the "YES" card in his holder. Support persons in Justin's various environments were also taught to ask Justin yes and no questions which were concrete and, if possible, offered some visual cues (e.g., "Do you want to go to gym?" while holding a picture of the gym; rather than "Did you have fun in gym yesterday?" with no visual reference).

It should be noted that people in all environments - school, home, and the weekend respite program - worked closely together to have as much consistency in design and use of Justin's augmentative choice systems. This consistency, as well as the fact that all support persons believed in allowing Justin to experience the natural consequence of his

choices appear to be increasing Justin's choice-making skills.

As a team, all of Justin's sites have decided to target the following choice-making goals for the next six months:

- Introduce other community jobs to allow Justin some choice as to which he prefers over others
- Introduce new regular education classes to begin to allow Justin to have input into his high school curriculum
- As other high schoolers are allowed to choose what units they want to participate in during gym, allow Justin this same choice through pictorial means
- Expand his community-based instruction to include choice-making for buying clothing and personal hygiene materials.

Chapter 7

Choosing my Friends and Lovers

Choosing My Friends and Lovers [16]

No discussion of choice-making opportunities for persons with developmental disabilities would be complete without recognizing that no more basic right exists, and no more fundamental choice is made by anyone than with whom they choose to associate. As mentioned in Chapter 5, the design of service delivery systems, especially with respect to residential services can enhance these choices for persons with developmental disabilities. Residential service providers need to look for opportunities to promote the development of friendships and respect the friendships which exist. The individuals should be permitted to choose their roommate, choose whom they accompany on recreational outings, etc. Seat assignments at meals and other events throughout the day can be designed to encourage the development of meaningful relationships.

Persons with developmental disabilities frequently have a poor history of developing interpersonal relationships and need specific structured training to improve their skills in these areas. As with other skill areas, experience with developing friendships will greatly enhance the individuals' skills in these areas. Often persons with special needs have been sheltered throughout their life from peers. The children go to school, come home and never have the opportunity to play with the

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[16]This chapter is based, in part, upon information presented by Ms. Orieda Horn Anderson during her presentation to Little Friends, Inc. on May 6, 1992 and her curriculum, Teaching Strategies for Instructors of Sexuality, Human Growth and Development.

other children on the block. The greater the degree of social isolation, the more likely that the individual will not have had the opportunity to develop a knowledge of the formal and informal rules that apply to interpersonal relationships.

Adults who have spent significant time in large congregate care facilities may not have been exposed to an environment with traditional expectations for behavior. As a result, sometimes they do not pick up the cues which members of the society give each other to modify behavior and sometimes even when they appropriately indicate their desires, those in the artificial environment do not or can not respond. As a result, basic social skills such as knowing the proper distance to stand from someone in a social situation, how to ask for information, how to indicate that you like an individual, or how to indicate that you do not wish to be in the company of another, are lacking.

Curriculums for Sexuality and Relationship Training

Several excellent curriculums are available to structure the teaching of basic social skills to persons with developmental disabilities. The James Stanfield Publishing Company of California produces several resources including the "LIFE HORIZONS I"[17] and LIFE HORIZONS

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[17]Winifred Kempton, Life Horizons I, The physiological and emotional aspects of being male and female. (Santa Barbara, CA: James Stanfield Publishing Co.)

II"[18] materials, "CIRCLES"[19], and "MIND YOUR MANNERS."[20] Another curriculum, Social Skills for Severely Retarded Adults,[21] is targeted towards persons with significant challenges.

At Little Friends, Inc. we have combined aspects of several of these curriculums into a training program which we call **STARS** training -- Special Training About Relationship Skills. It has been our experience that with the formal curricula adaptations and individualization needs to occur to meet the needs of our population. Individual residents have different skill levels and attention spans which affect the course of training. We found that the local library and the County Health Department are valuable resources to lend audio-visual materials such as videos, posters, anatomical models, and samples of birth control materials.

Basic sexuality information needs to be shared with everyone, including persons with disabilities. Persons with developmental disabilities are sexual beings and not a third, sexless gender as society has historically treated them. As support staff we must not only

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[18]Winifred Kempton, Life Horizons II, The moral, social, and legal aspects of sexuality. (Santa Barbara, CA: James Stanfield Publishing Co.)

[19]Champagne, M., and Walker-Hirsch, L., Circles I, II, and III. (Santa Barbara, CA: James Stanfield Publishing Co.)

[20]Mind Your Manners. (Santa Barbara, CA: James Stanfield Publishing Company)

[21]Mc Lennon, Hoekstra, and Bryan. Social Skills Training for Severely Retarded Adults (Champaign, IL: Research Press Publishing Company)

recognize a person's sexuality rights, we must re-educate ourselves to dispel the myths about sexuality and the person with disabilities. Some of these myths are that persons with developmental disabilities have no sexual needs, that they do not even understand the word sex or what it means, that they cannot control themselves once they begin having sex - that they will want to have sex all the time! Many persons believe that females who have developmental disabilities are more promiscuous than other women. Through the years, these myths have resulted in a general societal ban on sexual activity for persons with developmental disabilities. For the most part this cultural position has made it very difficult, if not impossible, for a person with disabilities to obtain correct information concerning sexuality. Thus, systematically we have limited their ability to make informed decisions.

In our society today we must acknowledge that being informed about matters of sexuality is not only a birth right but also an absolute necessity to preserve life in light of the possibility of HIV virus infection. Allowing any person to be sexually uneducated increases the risk of transmission of HIV and other sexually transmitted diseases. This results in greater risks not only to the persons with developmental disabilities but also to the personnel that work with them as well (i.e. support staff, nurses, doctors, dentists, etc.). By providing instruction in health, relationships, and sexuality and by providing opportunities for choice-making in the area of interpersonal relationships, sexuality and other areas of human rights, we assist all individuals to live a more normalized lifestyle.

Sexuality Policy

Prior to introducing a sexuality education program or curriculum, it is strongly recommended that there be a sexuality policy developed within your agency. Ms. Orieda Horn Anderson provides a guideline for agencies that will help them to develop a policy on sexuality. She stresses that each agency must look to the needs of their community and individualize the policy accordingly.

Sexuality Policy Development

Below are some suggestions on writing a policy. Just remember each agency is unique and various adaptations need to be made to address that uniqueness.

I. ***Assumptions:***

A. That all people are sexual beings. It is a birth right.

B. No illness, injury, birth defect, institution, government, agency has the right to cancel that birth right.

C. All people have a right to appropriate sexual expression based upon their capabilities and their potential.

D. This is not just talk and lip service. These policies are to be implemented.

II. ***Goals:***

A. Prevent exploitation.

B. Prevent the mentally retarded person from being rejected by the community for inappropriate social or sexual behavior.

C. Prevent unwilling experimentation which could lead to devastating social and emotional consequences (pregnancies, Sexually Transmitted Diseases - STD's, etc.)

D. Enhance self esteem by providing appropriate methods of self expression.

III. ***Objectives or Issues to be Addressed in a Policy:***

A. Dealing with homosexuality

1. Situational and other (Sexual Orientation)
2. Parent and Care-giver issues.

B. Teaching individuals appropriate ways of showing and accepting affection.

C. Masturbation

1. Allowing masturbatory responses in appropriate places.
2. Teaching and assisting clients who need information concerning masturbation.
   a. How to teach?
   b. Who does the teaching?

C. Personal hygiene.

1. How to teach?
3. Who does the teaching?

D. Sexual rights of individuals with developmental disabilities should be accepted by the parents, staff, and community, etc.

E. Sexual abuse, the sexually abused, and the abuser of the developmentally disabled.

F. Educational issues: Teaching basic sexuality information, birth control, sterilization, and other pertinent information.

1. How to teach?
2. Who does the teaching?

G. Procedures in the event of pregnancy.

H. Addressing the sexual issues in marriages with individuals who are developmentally disabled.

I. Education of parents, guardians, and family members to become aware of the sexuality of their developmentally disabled family member.

J. Privacy in a four bedroom living arrangement.

K. Consenting adults.

L. Conjugal visiting and where.

M. Pregnancy liability.

N. Addressing the sexual issues of the closed-head injured individual.

A policy governing sexuality issues must be generated through the agency's administration and approved by the governing board to have sanction. This policy will serve to protect as well as guide the agency and staff in delicate issues which arise. The Colorado Developmental Disabilities Planning Council developed a comprehensive policy document covering the sexual rights of persons with disabilities in 1990.[22]

To inform the agency administration and board of the need for a sexuality policy it has been extremely helpful to provide them with documentation of situations and incidents which occur involving sexual issues through an established reporting procedure.

Guidelines for Sex Education Programs

Three points to be considered in implementing any sexuality education program are:

1.) You cannot over-educate for the age.

As mentioned earlier, a review of the literature provides no conclusive evidence to support the hypothesis that informing persons about human sexuality increases sexual activity. It is preferable to err on the side of over-education of the individual than under-education. Given the diversity of learning styles and cognitive abilities of persons

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[22]Sexuality Rights Protection Policy, Colorado Developmental Disabilities Planning Council, 777 Grant, Suit 410, Denver, CO. 80203

with developmental disabilities, it is strongly suggested that an instruction be given using more than one modality. Using actual pictures and three dimensional models of both sexes may be necessary to concretely transfer sexuality information being taught.

2.) Everyone must have an understanding of proper terminology to better communicate their personal needs and wants.

It is important to remember that the individuals receiving the sexuality instruction come from a variety of backgrounds. Before proceeding with instruction, it is important to insure that the teacher clearly understands the sexual vocabulary of the student. The use of too many clinical labels for parts of the human anatomy may confuse the learner if he only knows that body part by a slang term. As discussed in chapter two, augmentative communication systems may be necessary to meet an individual's needs. Various communication systems can be developed to include the material which will be covered in the sexuality and relationship training.

3.) All information has to be kept in perspective.

When providing instruction and counseling to persons regarding sexual issues, the instructor must be aware of their own cultural beliefs and moral values. When an individual is making a choice regarding his or her sexual behavior, that behavior will be evaluated within the

context of the community within which they reside, and compared with the behaviors of non-handicapped peers. The behavior is not evaluated solely based upon the values of the Instructor. Persons with developmental disabilities have the right to make the same unwise choices regarding their personal relationships as every other person in the community.

Assessment of Need for Training

The individual's needs for sexuality education may be assessed through formal and informal methods. Formal assessment tools are included in most structured curricula for sex education. These may require individualization and augmentation based upon the person's learning and communication abilities. Informal assessment of the need for sexuality education may be completed through the evaluation of observed incidents of the individual's behaviors, both appropriate and inappropriate sexual behavior. Objective documentation of situations and incidents which occur will be helpful in compiling an accurate assessment of the person's knowledge and ability to make choices regarding relationships. In evaluation of behavioral incidents, a determination should be made about the primary issues present in order to determine the type of intervention required. Does the issue concern human rights? Is the problem the result of behavioral deficits? Does the individual have a lack of necessary information regarding his options? Does the individual have weak problem-solving or communication skills? Is this a self-esteem issue and the individual

lacks confidence, etc. ?

At Little Friends, Inc., we began formal and systematic assessment of residents' sexuality as part of our futures planning process. We chose an evaluation outline for sexuality in the "SCIL Program," Systematic Curriculum for Independent Living, Volume Three,[23] and adapted it using slides from Life Horizons I and II curriculums to provide visual material to aid communication and understanding. Data from the objective documentation of incidents in our assessment sexuality expression experience was also included. When conducting an assessment, it is important to remember to preserve the person's dignity and privacy. The interviewing person should be someone who is knowledgeable about sexuality and able to remain objective and supportive during the process. Depending upon the person's attention span, communication skills, and comfort level, several meetings may be required to obtain accurate information. From this assessment, we were able to identify areas for instruction and support. The person then indicated, through the futures planning process, which areas they wanted in their individual habilitation plan. All agencies may not be set up for such a systematic planning process. However, it is important to promote, on your own scale, the principles of dignity, privacy, and choice in the area of sexuality.

In each case, the type of intervention required will be different. In one situation, structured education and instruction may be

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[23]Hannah, M., Millhouse, J., and Sauvageot, A., et.al., SCIL: Systematic Curriculum for Independent Living. (Novato, CA., Academy Therapy Publications, 1977)

warranted. In another situation, counseling may be required. Other options for intervention include behavioral programming, or medical intervention. The response is always based upon the individual circumstance and the individual persons involved.

It is important that when a support staff person encounters an inappropriate sexual situation to:

1.) Be objective.

2.) Consider the situation and environment.

3.) Respect and preserve everyone's dignity.

4.) Teach appropriate behavior.

5.) Maintain confidentiality of the individuals involved by documenting these incidents and reporting them only to those persons that need to know.

Remember, open communication between staff and the individuals involved will serve to model and enhance the understanding that sexuality is a natural aspect of everyone's life, including that of a person with disabilities.

Case Study

Situation 1:

A member of the support staff at a residential facility observed a male and female client on several occasions in the hallway and outside at the picnic table engaged in prolonged kissing. This is a very public area and several other clients reported discomfort about observing this behavior. The staff member also observed several clients on one occasion asking this couple to cease saying," Knock it off", which was ignored by the couple. Both individuals involved are legally competent.

The incident was documented and a referral made to the Social Worker - a procedure usually followed in our agency. During counseling sessions which followed, the couple was informed about their options for expressing their sexuality. They received information regarding the need for intimacy, and the need for privacy in relation to various settings.

The Social Worker provided information to the couple about how others' feelings of discomfort and the possible social consequences of their activity should affect their choices. They received training about how to access various private settings, and what environmental cues to look for to determine when it's appropriate to discontinue affectionate behavior. The Social Worker found that a role play of environmental cues was helpful to convey concepts. The couple decided to try to watch for those cues and asked the support staff to help them arrange for some privacy time to meet their intimacy needs.

Human Rights Issues--	Social/civil consequences of inappropriate sexual behavior; sexuality needs/rights.
Behavioral Issues--	Self-control.
Skill Deficit Issues--	Limited knowledge and experience about types of sexual expression appropriate to the setting; how to arrange for privacy , how to discriminate settings and behaviors, and use of communication and relationship skills.

Situation 2:

When the support staff boarded the shuttle bus to follow up on a client request, they observed another client couple positioned in a sexually suggestive manner. The staff person quietly prompted the couple that they should sit upright to avoid serious injury should the bus stop suddenly or be involved in an accident. The couple agreed. The female resident is legally competent, the man involved has a guardian of the person.

The staff person got off the bus, recorded the incident and made a referral to the Social Worker. The Social Worker met with the couple later, in private, to discuss the staff's observation. This helped the couple to identify the discrimination error made regarding public vs. private setting. The Social Worker pointed out the possible social or civil consequences of their activities, and options available for to them for privacy. The couple chose to refrain from that type of intimate

behavior in a public setting and schedule some privacy time to meet their sexuality needs.

Human Rights Issues--	Social or civil consequences of inappropriate sexual activity in public setting; sexuality needs or rights.
Behavioral Issues--	Self-control.
Skill Deficit Issues--	Limited knowledge and experience in discrimination of settings and appropriate behaviors.

Situation 3:

Instructional staff receive a request for assistance from female resident to budget and to make arrangements for an over-night date with boyfriend. Both individuals are their own guardians.

The request was documented and a referral was made to the Social Worker. The Social Worker discussed the request with each client individually and in private to assess mutuality of consent, knowledge of birth control methods, and contagious disease prevention. The man expressed concern about pregnancy prevention and requested information and instruction in the use of condoms. The woman stated that she had completed a class in sexually transmitted disease prevention and condom use and requested assistance in the purchase of birth control devices and budgeting for and making motel reservations. Both residents indicated that they had discussed the desire of engaging in sexual intercourse and the options available for privacy. Mutual

consent was established contingent upon the resolution of the male client's concerns about pregnancy. The Social Worker encouraged both individuals to discuss these issues with each other and then set up a time later to discuss their decisions and any other concerns with the Social Worker.

Later the couple returned and met with the Social Worker. A discussion of the possible consequences of unprotected sex was the major topic. The couple decided upon the use of condoms and spermicidal vaginal suppositories. The couple determined which staff person they wanted to give them instruction in use of these products. The couple decided that they would take turns in providing the financial resources for the birth control supplies, dinner, and a motel room. They divided up the responsibilities for making room reservations, dinner arrangements and purchase of birth control. The Social Worker asked them to keep her informed of their progress in implementing their plans for the date. Possible emotional issues were discussed. The option of changing their minds and suggestions on how to communicate their desire to wait on the intimacy and just have private time in the motel was given. The Social Worker also suggested that together they discuss their privacy and decide how they would protect it. After both individuals reviewed the use of the birth control methods they had chosen, the devices were budgeted for and purchased. The couple proceeded with deciding upon and mutually available evening and making arrangements for their date. The couple had their date. The male client stated later to the Social Worker that everything went well. He requested further information about other birth control methods and

asked for assistance to obtain it through the Health Department.

The reader should note that the Social Worker had knowledge that this couple had begun to plan such an overnight date about a year earlier in their relationship, and chose not to follow through because they expressed unreadiness. Also, both had completed STARS Relationship Training a year earlier.

Human Rights Issues--	Confidentiality, mutual consent.
Behavioral Issues--	None
Skill Deficit Issues--	Use of birth control methods chosen, ability to mutually discuss problems and concerns, budgeting.

Situation 4:

A female client reported to the Social Worker that male client laid on top of her the previous evening in the Recreation Room, holding both of her wrists to the floor while trying to kiss her. She stated that saying his name, saying "NO" and threatening to tell staff did not seem to stop him from engaging in this unwanted activity. She was not sure what caused him to let go of her. She stated by demonstration that she also turned her face away. She reported that she did not like it and wanted to know how to handle the situation if it happened again. The female client has a guardian, the male client does not.

In this situation, the Social Worker validated female's feelings and verbally reinforced her choice to report the incident. She informed the female client of possible ways to express her dislike of the male

client's behavior. Together they explored her options and the possible consequences of each for herself and the male client. The Social Worker then asked the female client if she would like her guardian to assist her in making decisions. The Social Worker instructed female client in the use of her voice to yell for help through role plays. The female client chose to ask male client's Case Manager, with the proximity support of the Social Worker, to discuss the incident with the male client and to instruct him in how to request permission before kissing someone (outside his family). The Social Worker also requested that the male client be taught cues to listen and watch for in regards to consent or refusal. The Case Manager also recommended that the female client check in with staff when she came on the men's floor to visit to notify them of the need for monitoring future behavior of male client. The female client agreed to this plan. The Social Worker documented the incident to record the need for further skill instruction. The female client's Case Manager was informed of the incident and the proposed resolution.

Human Rights Issues--	Mutual consent, sexual harassment, confidentiality.
Behavioral Issues--	Self-control, aggression.
Skill Deficit Issues--	Weak communication, relationship and environmental discrimination skills.

Case Study -- Debra

Overview

Debra is a thirty-six year old woman with mild mental retardation, epilepsy and borderline personality disorder. Currently, she works at a sheltered workshop. Previously, she was employed in janitorial and food services in the community but layoffs at her job site earlier this year necessitated her return to a structured vocational setting while other employment options are evaluated. During the past five years Debra has resided in a Community Living Facility.

Debra is able to read, write and perform simple math calculations. She is verbal, although at the beginning of this study, 3 years ago, she seldom directly communicated concerns or needs until staff observed non-verbal indications of distress and prompted her to state the problem.

Debra engages in some passive-aggressive displays of exaggerated mannerisms in lieu of assertively expressing dissatisfaction and often states concerns about others in their presence in the third person. Debra sometimes responds to feedback, neutral or critical, with intense emotional outbursts which may include behaviors such as: yelling, screaming, verbal hostilities, aggressing objects, aggressing persons, crying and making false statements.

Debra is a survivor of child sexual abuse. She receives counseling, behavior management and psychiatric services in addition to regular ILS (Independent Living Skill) and vocational support services.

Relationship skills

About three years ago, Debra verbally expressed her desire to re-kindle her relationship with a male friend named Tom. After Tom was consulted by his residential program counselor, the couple agreed to the suggested participation in a class about relationships and sexuality. The class content included information about how to discriminate the appropriate type of intimate behavior relative to relationship and setting; how to obtain mutual consent; and how to arrange for privacy in addition to factual information about human reproduction, birth control, sexually transmitted diseases (STD), and sexual abuse prevention. Over the course of a year Debra and Tom met weekly with counselor(s) to complete curriculum objectives.

Near the end of the course, during counseling, Debra began presenting her needs and concerns about intimacy and desire to make a serious commitment to the relationship with Tom in marriage.

Evaluating their options

Debra and Tom generated and discussed their options for intimacy and commitment with the counselor. The major options considered, with variations thereof, were:

- Sexual intercourse in private setting before and after marriage;

- Sexual intercourse in public setting before and after marriage;
- Sexual intercourse in a semi-private setting before and after marriage;
- Sexual intercourse with and without using birth control methods;
- Sexual intercourse with and without STD prevention;
- Co-habitation before and after marriage, with and without CILA services;
- Intimate behavior excluding sexual intercourse in various settings prior to marriage.

Debra and Tom thoroughly discussed each of these issues with the counselor. The counselor asked about and related general information to Debra and Tom in each area noted above. The counselor suggested that Debra seek out information from a sampling of sources with **personal** relevancy (ie. family, trusted friends, boyfriend, pastor, or physician) to assist her in making a more informed choice. Time was spent initially assisting Debra to determine what information she desired by compiling a list of questions.

For moral guidance about sexual intercourse prior to marriage, the counselor suggested that her pastor (Debra is a practicing Catholic), family, and perhaps supportive friends might be consulted. Debra decided to initiate the process by scheduling a meeting with her assistant pastor. She stated that she was more anxious about approaching her family so she gave the counselor consent to discuss

some general information about her relationship with Tom to her parents. Tom also gave consent. The counselor then assisted and supported Debra and Tom in expressing the seriousness of their relationship to their parents.

Implementing Choices Made

In the area of birth control, the counselor made the suggestion that Debra consult her doctor about the options and any health risks specific to her case. Debra was comfortable with initiating the discussion with the program nurse who then set up a consult with Debra's physician upon her request. Debra also discussed the topic with her pastor, mother and sister. The latter two initiated the topic with Debra based on their own concerns. Debra was also reminded that Tom's feelings and needs would need to be considered for any option to work. Debra also decided to discuss with Tom their future plan for parenthood.

The counseling sessions now dealt with practical ways to implement the choices which Debra and Tom have made. The counselor reviewed the sexuality policy at her current residential placement. Debra had agreed, at the time of placement, to adhere to the policy which prohibits sexual intercourse at the Community Living Facility. Debra and the counselor discussed her private setting options (ie. motel or Tom's apartment), and future residential options (family, residence hall, apartment) before or after marriage. Debra was able to identify areas which would be difficult for her to manage in an apartment (her

first and desired choice). Debra then decided to apply for CILA services. She completed the application with the assistance of staff and parents (asking appropriate persons for missing information). She misplaced the application before submission and repeated the process. She is currently on a waiting list.

The Results

During this time Debra and Tom agreed to periodic monitoring during privacy visit in Debra's suite. This procedure was developed to teach Debra how to arrange for privacy and express her needs for intimacy within the parameters of a semi-private setting. About this time Debra and Tom informed both families of their intent to marry after an engagement period.

Debra took the information she learned from the consultations about her birth control options and made the decision to investigate the option of tubal ligation. She had decided upon this option because of the health risks of some of the options with her epileptic condition and because, as she explained, she lacked the desire, skills and patience to be a parent. Tom supported her decision. Debra attended a consult at a university hospital clinic and completed the mandatory one month waiting period, following through on her decision the next spring.

Later that fall, Debra and Tom began visiting more outside the CLF at Tom's apartment. Debra asked that Tom receive some information and training in the management of epilepsy. Tom agreed and completed the orientation. Tom learned how to arrange for some

privacy with his apartment roommate. When Debra's family began to pressure them about the amount of time spent together, Debra and Tom decided to withdraw the consents enabling staff and family to discuss their visitation and relationship, thus protecting their privacy.

Recently this spring, Debra and Tom picked out their engagement and wedding rings and are paying for them on an installment plan.

As the reader can review, Debra's skills in choice-making in the area of sexuality and intimate relationships have evolved over a period of three years. During this time she has learned to generate more options independently, has been able to approach significant and appropriate persons more independently to gather information to evaluate her options, and has become more confident and independent in making plans and acting upon them. Many hours of consultation and training, based upon the premises of respect and capabilities, were provided by staff. Many times Debra and Tom needed support at many different points of the choice-making process. During the three years, many issues (ie. emotional, vocational, health, etc.) were addressed as they arose. Debra and Tom learned how each choice which is made can effect other areas of your life. Also, because transitions are difficult for Debra, prior education, role-play and plan development for implementation of choices were essential to empower Debra to attain a higher level of self-fulfillment.

Chapter 8

Self-Advocacy and Choice-Making

Self-Advocacy and Choice-Making [24]

Self-advocacy is a natural outgrowth of choice-making. So far, our discussion of choice-making has assumed that support personnel are largely responsible for taking the initiative to identify choice-making opportunities, and for helping the individual to secure the assistance they need in carrying out their choices. Self-advocacy takes this process one step further by addressing the individual's need, as a citizen with a disability, to understand and advocate for his or her rights and to help shape the laws and practices affecting support service provision.

"People First" is an international self-advocacy group organized by individuals with developmental disabilities. Tia Nellis, of the Naperville, Illinois Chapter of People First, describes how the group helps members as they experience the challenges and satisfactions of actualizing their choices:

> People First gives you the opportunity to make a mistake. A lot of times people will say, "Oh, but they can't do that - don't let them make that mistake" - because they have a disability and they protect them, and they don't let them try to learn from their mistakes...and that's how our group helps each other. We support each other, we help each other and we're there for each other. Even when we make mistakes, we're there to pick each other up, and it's OK to fall on your face because you can get back up again....we learn from our mistakes, and it's really great.

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[24]This chapter is based upon the information presented by Tia Nellis, a member of the Naperville Chapter of People First during her presentation to Little Friends, Inc.

In a People First group, the members are responsible for setting the agenda and running the meetings. Each group has an advisor (someone without any obvious cognitive impairment) whose role is to provide ideas and support to the group, but not to direct the group. People First chapters act on both a local level - within the confines of a particular congregate care facility, for instance - and at the state and national levels, by acting as lobbyists and public speakers on topics related to the rights of persons with disabilities.

Organizing a Self-Advocacy Group

If an organization wishes to encourage the establishment of a People First chapter or similar self-advocacy group, they should follow these guidelines in order to be effective. First, it must be realized that self-advocacy, in order to be at all meaningful, must be generalized beyond the context of meetings. It is fruitless to have self-advocacy be a scheduled "program", where participants are sent to a room for an hour to discuss their right to be self-determining, only to return to an environment where their opinions are not sought, and their choices are not honored. Thus, an organization must be ready to support self-advocacy throughout its daily operations as well as through the encouragement of a group. Second, the personnel assisting the group must resist the urge to do too much. As Tia Nellis points out, an important part of the self-advocacy experience is taking responsibility for one's choices and learning from one's mistakes. Staff have to let go at some point and allow participants to be in control of the group.

People First also provides suggestions for how an organization can promote self-advocacy. One way is by providing information, education and training to the individuals served. Another way is by creating opportunities for individuals to make decisions wherever possible within the service delivery system. The organization should seek input from individuals on their support plans (IHP's, IEP's, etc.) as well as on policies and procedures that affect the persons being supported.

In order for people to advocate for their rights, they must be aware of what those rights are. Although organizations providing support services are generally aware of the need to notify service recipients of their rights, this often is a mere formality - the act of obtaining a signature on a piece of paper - rather than a serious attempt to educate the person. An individual should have their rights explained to them in language they can understand. An example of a simplified rights statement is given at the end of this chapter. Further, the organization should be ready to take these rights seriously and to act immediately on any complaints from consumers regarding the abridgement of their rights.

Self-advocacy operates on the premise that persons with disabilities are citizens with the same status in society as any other group. Self-advocacy thus extends beyond the individual's personal relationships to participation in the democratic process. Individuals with developmental disabilities should be given information on their rights as voters and as constituents. They should be given the opportunity to be aware of public issues that affect their well-being and of the actions they can take to affect the legislative process - such as

writing to their representatives, attending public meetings, etc. Through self-advocacy, persons with developmental disabilities can learn not only how to make choices, but how to work within the system to ensure that they have the full range of choices available to them.

Rights Of People Receiving Agency Services

A statement should be signed by each person receiving services (or parent/guardian, if appropriate) acknowledging that she/he was informed of her/his rights and understands them upon beginning to receive agency services.

A "**right**" is something that anyone can have or do, just because they're a person. Some things are not rights. Prescribing medications is not a right--you have to be a doctor to be able to do it. Asking to go and see a doctor because you think your medicine isn't working is a right--anyone can do it. Sometimes people with disabilities don't understand everything they are able to have or do. They think that because they have a disability, or because they have "staff" who work with them, they don't have as many rights as other people. That's not true; the only way you can have fewer rights than other people is if a judge in a courtroom says you need someone else to make decisions for you or if you go to prison. Some of the things you should know about your rights are:

- No one can take away your rights just because you have a disability.
- You must not be ignored, hurt or treated badly by staff, other participants, or anyone else.
- No one may hit you, yell at you, call you bad names, or make you feel bad about yourself.
- You do not have to be part of an experiment, if you do not want to.
- You have the right to take care of your own money. If you have a guardian, that person will help you. You or your guardian may ask a staff person to help you take care of your money.
- You have a right to participate in staff meetings where people decide what kinds of things you need to learn to do. You have a right to tell people what you want to learn how to do, and they have to listen.
- You have the right to receive, buy, own, and use things that you like (such as radios, TVs, hair dryers, etc.).
- You have the right to buy, choose, and wear your own clothes.

Chapter 9

Families and Choice

Families And Choice

> ***"In the end, we're all going to have to let go of our children - the children we teach, the children we parent - while hopefully leaving them with something to hold onto. And how much better for them, and for us, if the something they have to hold onto is something that they've had a hand in choosing, and that we've had a hand in making possible as a choice."*** [25] [26]

For families, life with a person with a developmental disability often means giving up many choices that more typical families have. Parents may have to change or give up their careers, their free time and their financial security in order to provide the supports their child needs. Siblings may have to give up their fair share of attention within the family and the ability to be a typical kid because of the needs of their brother or sister. Sometimes, it seems that the daily lives of the entire family come to revolve around the needs and demands of the child who is disabled.

Any family which includes a member who has a developmental disability is subject to stress in various forms. Parents experience a grieving process when they first find out that their child has a disability; this grieving process may be re-lived over and over again, as

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[25]Steve Meckstroff, Member, ISAC Training Team

[26]This chapter is based, in part, upon the information presented by Mr. Steve Meckstroff, and Dr. Paul Bates, Ph.D., professor at Southern Illinois University during their separate presentations at Little Friends, Inc. during 1991 and 1992.

their child successively encounters the milestones of growing up and often fails to make the same strides as his or her peers. Occasions that bring happiness for other families, such as holidays, vacations and birthdays, can be fraught with feelings of frustration, anger, and sorrow because of the ways these events highlight the family's inability to live a normal life and the child's inability to participate in a typical fashion.

When families come to us as service providers for assistance, it is crucially important that we try to appreciate the tremendous stress, emotional upheaval and difficulties that they experience. All too often, the mechanisms they have found to cope may be dismissed by us as "dysfunctional" or "overprotective." On the other hand, we may see a family as being uncommitted to their child with a disability when in fact they have reached a point of such exhaustion and disillusionment that it is hard to work up enthusiasm for yet another program or professional.

Families - Where choice begins

One of the most important things for support persons to do in working with families is to recognize the things they already do to help the person have choices. Parents instinctively try to recognize their child's desires and preferences: this begins as early as the parent trying to decipher whether a baby's cry means that she wants to be fed, held or changed. A parent whose child has a developmental disability may have learned to understand unconventional means of communicating choices, such as through gestures instead of speech. Parents may also

try to find substitute choices for children who reject more typical choices: giving the child objects to use for self-stimulation, for instance, when he rejects toys. To professionals, it may be tempting to reject these efforts because they seem to encourage inappropriate or stigmatizing behaviors; however, it is more productive to view these adaptations as a step towards recognizing the person's preferences, and something to build on rather than something to eliminate.

Assessment

One of the first things service providers can offer in helping a family to expand their child's range of choice-making is objective assessment. This is something that is difficult for families, as they are so intimately involved with their child. Objective assessment does not have to entail destruction of the family's hopes for their child; the best assessment is one which focuses on what the person can do and where there is potential for growth, while at the same time being honest about the person's current skills and behaviors.

Identify Resources

Another thing service providers can do is to help families identify resources and strengths that exist both within and outside the family. This can include personal resources, such as faith, philosophy and organizational ability, as well as relying on extended family members for support. External resources such as advocacy groups, support services

and other community resources are also crucial in providing help to families. By enabling the family as a whole to cope and to have more freedom, we can enable the family's ability to give their child a wider range of choices.

Communication is the key

One of the most important things service providers can do is to keep lines of communication open. Both professionals and family members need to remind themselves of their shared goals on behalf of the individual, and actively fight the tendency to place blame on one another for failures that occur. Service providers must realize that sometimes what they have to tell families is not going to be easy for them to hear, and may not be accepted the first time around. This does not mean that the family should be dismissed as being irrational or uninvolved. Staff should remain tactful, persistent and patient in their efforts to involve family members in planning for the individual.

Sometimes, families and service providers may lock horns over issues involving choices for the individual. For instance, parents may insist that a certain type of setting or opportunity, such as a community job, is preferred by the individual while the staff involved feel that the person actually prefers and gains more from involvement in a different type of activity, such as sheltered work. Conversely, families may oppose efforts to enact choices expressed by individuals if they feel the choice isn't in the person's best interests. In these situations, staff may be tempted to interpret the family's behavior as "wishful thinking" or

"overprotective". A more constructive approach would be to actively engage the family in discussion of the issue and try to delineate their reasons for supporting one alternative or another. For instance, it may be that a person's family is leery of letting them experience a given opportunity (such as community employment or supported community living) because they fear they will fail and not be able to return to the existing program of services. If staff can be sensitive to this fear, it may be possible to offer assurance that the person will be able to return to their present living or day program arrangement if the new arrangement doesn't work out. Service providers also need to be open-minded. If a person's family pushes for an opportunity that would appear to be beyond the individual's capability to handle, it may be that the family has a clearer idea of what the person is capable of in other settings. Perhaps a compromise can be reached where the individual is able to be offered the option on at least a trial basis, rather than simply dismissing the family's opinions.

Assertiveness Training

Sometimes situations arise where an individual is afraid to assert his or her actual preferences to a family member or guardian. This can create frustrating situations, where the person expresses to staff that they want one thing, then "caves in" to pressure from their family members when given a chance to discuss it. If a person is having trouble advocating for their own goals, assertion training can be used to enhance their skills in this area. Assertion training involves teaching

the person to discriminate between assertive, aggressive and non-assertive behavior and to understand what type of behavior is called for in various situations. The individual should practice using self-assertion skills in more mundane situations before being encouraged to take an assertive stance with their family. Researchers such as Dr. Paul Bates of Southern Illinois University have developed models of assertion training specifically designed for use with persons with developmental disabilities.

Families can also be helped by giving them feedback on the need for the person to express their individuality and to be more self-determining as a normal part of the process of maturation.

It may be difficult for families to see the individual with a disability as being an adult. Service providers can help by modeling adult interactions with the person and by continuing to provide opportunities for adult activities and roles within the context of service provision.

Case Study

Amanda is a fifteen year old girl who has autism and mild retardation. She attends a small alternative high school with a vocational component. During Amanda's school day, she participates in three academic classes, a life skill class, work adjustment training, and a social skills class. She receives community based instruction at least twice a week.

Amanda resides in her family home with both parents. Her mother is extremely involved with Amanda and uses a very controlling parenting style. She keeps Amanda and her father apart because she believes Dad doesn't understand or know how to deal with Amanda. Mom controls Amanda's choice of food, clothing, rec-leisure activities and tries to impose herself on the educational process by telling teachers when to give Amanda homework, how much, and what classes she should have. Amanda's time is tightly structured by mom, and choice is usually not offered.

To transition Amanda into a more age appropriate role, basic choice-making has been determined to be a priority in her current educational setting. Teaching Amanda to communicate her choices is one of her instructional objectives.

Amanda's communication skills complicate her already disordered emotional functioning. Although she can speak in short sentences, she has very limited expressive communication skills. She does not initiate communication with peers or staff but will respond to direct concrete questions.

At school, Amanda has difficulty making choices. If two options are presented, and Amanda can see them, she will point to one of them. However, she will then look quickly into the presenter's face for approval. She will quickly switch her choice if she senses disapproval or gets no response at all.

Amanda has made some choices at school, such as where she will sit, what she will do during free time and what foods she will eat in a restaurant. There are other choices available to Amanda, but she does not take advantage of these choice-making opportunities. Amanda can choose which physical activities she would like at the YMCA or health club; which activity in the Life Skills class she will do (such as cooking or cleaning); and whether or not to participate in a recreation or leisure activity which is offered at school.

Developing Preferences

Amanda's mother has provided her with a variety of structured recreational experiences, including museums and travel, but Amanda has had very little experience in socializing with her peers. The family avoids neighborhood functions because they don't want Amanda to be made fun of. Amanda's mother is very conscientious of Amanda's diet. Her lunch is nutritiously prepared, and Amanda is never allowed to buy pop or treats from the school store or vending machines.

Amanda's problem with choice is two-fold. First, her autism prevents her from communicating her choice if she has one; and second, in Amanda's controlled life style, her choices are rarely considered. To

address the first concern, Amanda needs to be supported to develop an augmentative system which will help her to consistent indicate her choices. To address the second concern, counseling with the family, and especially with Amanda's mother is needed.

At this point at school, Amanda is not able to select options on her own. She needs options presented to her by staff. She deals better with limited choices. The current emphasis when teaching choice-making to Amanda involves broadening her experience base. If she makes a choice she doesn't like, she will either pace, flap her arms, or repetitively chant a phrase such as "I wish" or "I can't." If the choice was positive, Amanda doesn't react.

Because of Amanda's autism, she is not able to respond when presented verbally with options. She needs to see her options or have them listed on paper. She also needs her social experiences broadened so she can make these choices knowledgeably.

The family's role

The family will receive home visits from the Social Worker at the school to help Amanda's parents understand the need to let Amanda begin to have some control over her life. The training which Amanda is receiving at school will not be very effective unless her parents cooperate in the goals and objectives outlined in the IEP. In the past there have been several occasions when a choice was offered at school and mom has over-ridden Amanda's response. For example, a choice of field trips was offered to the students - they could go to the Sci-Tech

Museum or a pep assembly at a local high school. Amanda chose the assembly, but the following day, her mom called and said she wanted Amanda to go to the museum. It is essential that the Amanda's choices be respected if she is going to communicate effectively.